

**“I AM THE MOTHER AND THE FATHER”
THE EXPERIENCES OF ORPHANED CHILDREN CARING FOR CHILDREN
IN UGANDA**

by

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ABSTRACT

In Uganda, incidences of disease and social unrest resulting in parental deaths have created a large orphan population throughout the country. This study explored the experiences of orphaned children who specifically take on the role of being both mother and father to their siblings. The researcher had discussions with 34 child-headed households throughout Uganda over the course of three months. The young people discussed their experiences of loss, reactions of self along with the reactions of the community, the vulnerabilities they face, coping with loss and daily stressors, acceptance of the role as a parent, and their hopes for the future. The findings suggest that young carers engage in behavioural and environmental adaptations in order to forget, but when the methods of coping with the stressors affecting their daily lives failed, they were thrust into a grief response. Consequently they look to education to change their lives and release them from this cycle. Support should be strengths-focussed, community-based, trustworthy, dependable and accessible; while recognizing the trade-offs and choices the young carers are required to make on a daily basis. Further research is needed to look at the effects of education on creating a life change for this population of children, how forgetting helps them to move on with their lives and what effect that has on their future, and what formal support networks could help these children achieve their hopes for the future.

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DEDICATION

To all child-headed households in Uganda.

CHAPTER I

Introduction

Child-headed households are homes in which one child has taken on the primary caretaking role of his/ her younger siblings. In Uganda, this phenomenon has occurred largely as a result of parental deaths from disease and social unrest. The affect of this role upon the young people and the children they care for remains largely unknown. Boris, Thurman, Snider, Spencer and Brown (2006) argue that there is not enough data on children who have taken on the role of carer to generalize about their caretaking capacity. By studying the experiences of children in Uganda, East Africa, I am able to contribute to the understanding of how the lives of these children who are heading their house are affected, and how we can best support them.

For the purposes of this study, I have defined a young carer as a person under the age of 25 who provides unpaid care to a younger family member (Becker, 2004). Although the term orphans and vulnerable children (OVC) is used widely among organizations working in the country, for the purpose of this study and in order to connect it to the broader larger literature, I will use the terms young carers and child-headed households interchangeably. Orphans are defined as children who have lost both of their parents, sometimes termed a double orphan, and are currently living without adult supervision (UNICEF, 2008). In Uganda, children who are caring for sick relatives are also classified as child heads, but for the purposes of this study only those who were completely without an adult in the home were studied. Consequently in this study I define a child as being any individual under the age of 25 and over the age of 12. Participants of

this age range, as emancipated minors due to their circumstance, were able to give fully informed consent.

In this perspective, coping is regarded as a dynamic process that involves frequent contact between the person and the environment. It encompasses the ways in which a person thinks and acts in dealing with a stressful situation (Lazarus, 1993). However, Folkman et al. (1986) believed that it did not depend on whether the person's efforts at managing the demands are successful or not. Coping is also process oriented, contextual, and not good or bad. The two major purposes of coping include: regulating stressful emotions and changing the troubled person-environment relation causing the distress. These are often termed emotion-focused and problem-focused coping, and are found functioning side by side.

A qualitative approach was used as I placed an emphasis upon description and on the meaning of the experience to the participants themselves. Literature exploring the experiences of orphaned children caring for children in Africa is scarce. Therefore, this qualitative study, which is informed by grounded theory and is devoted to understanding the day to day experience of these young people, was the most plausible strategy for examining the central research questions. The overarching goal is to bring an understanding of their experiences with being a young carer. I believe that we have to hear their experiences to know what it is like to be a young person heading a house.

I have chosen to use strategies from grounded theory to inform this study. Grounded theory is useful in areas where there are major gaps in our understanding (Schreiber, 2001). Charmaz (2006) suggests that it helps us to study complex and hidden processes within people's actions and to develop theories that help us to understand them.

Therefore, it has this imaginative and creative aspect to it which allows unexpected events and experiences to emerge. These underlying ideas fell in line with this research because I wanted to discover rather than test something. I wanted to follow the lead of the young carers and co-construct knowledge with them because I felt like they had a lot to tell us. However, I did not want to just describe what they said as is true in many other methods of qualitative research. I wanted to construct meaning of their words, and understand them in a way that allowed me to create a practical model and practical ideas that could be useful and helpful in the future as more and more knowledge is accumulated in regards to the experiences of these young people.

The present study expands on the existing literature concerning child-headed households in Africa and in the Western world. In the first three chapters, I will describe the issues underlying the research and the methods used to shed light on the topic. Chapter IV focuses on the ethical issues that were prevalent throughout the study. In Chapter V, I will describe the themes that emerged in the data in their respective categories. In Chapter VI I will discuss the findings of the research and present a conceptualization that explains it. Finally, in Chapter VII and VIII I will look at the limitations of my study, the implications for social work practice, future directions for research and my concluding remarks.

CHAPTER II

Context

I could have undertaken this study in a number of countries in Africa that have large orphaned populations. I attempted to make contact with potentially interested parties in a number of locations. However, I chose Uganda as I was able to make contact with Dr. Doris Kakuru. She is a professor in the Sociology Department at Makerere University in Uganda's capital city. She has an interest in my area of study and was crucial in connecting me with the local leaders and the organizations that had access to the young people in the communities. Local contacts and support are, of course, critical when carrying out studies in other countries both for access to the population and assisting in manoeuvring through the local research requirements.

Uganda borders Tanzania on the North, Kenya on the West, the Democratic Republic of the Congo (DRC) on the East, and Sudan on the South. For over 25 years, the Ugandan government has been fighting the rebel group Lord's Resistance Army (LRA). The extensive number of adult deaths in this conflict has resulted in a large orphan population. Along with the social unrest dominating the northern part of the country, Uganda is faced with widespread disease. East Africa has a higher national HIV prevalence than Central and West Africa. Uganda's HIV prevalence rate is at 6.4 percent (The World Bank, 2006), and although it has dropped significantly since the early 1990's, many children and families continue to be affected by it. According to UNAIDS (2002), in 2010 Uganda is expected to have 3.5 million children under the age of 15 orphaned by AIDS. This study has focused on Gulu district in the North, Rakai district in the South, the capital city Kampala, and Jinja district in the East. A map showing the different areas

studied can be found in Appendix I. These districts were chosen upon the advice of Dr. Kakuru. The districts each have high populations of orphaned children.

Political unrest in Gulu district (and other Northern districts) has existed for many years. Many families and children fled the north years ago to settle in Kampala. A camp set up in the city was the destination for some, while others ended up living on the street or in other areas. Road accidents, AIDS, and other diseases are also causes of death resulting in orphans in the capital. The first incidences of HIV/AIDS in Uganda were discovered in the Rakai district. This area had one of the highest infection rates in the world in the 1980's, and although it has decreased, many families continue to be affected (Leggett, 2001). Jinja district is on the road connecting Kampala to Nairobi in Kenya. As a result, this area has been affected by people travelling along this road. Drivers transporting goods are known to stop and have sexual encounters with women and young girls. This has resulted in the spread of AIDS with the expected resulting deaths causing an increase in the orphan population.

While there is a significant orphan population in Uganda, there are only a few national and international policies in place that purport to protect the rights of the children in Uganda. I will highlight some of the relevant ones for this study even though I do not believe that they have not been effective in dealing with the situation. In the Children Act, ratified in 1997, local government councils are given responsibility to safeguard and promote the welfare of the children in their district. The African Charter on the Rights and Welfare of the Child, which was enacted in 1999, stresses that every child shall be entitled to the enjoyment of parental care and protection. It also states that parentless children shall be placed in alternative care arrangements such as foster care or

institutions. In addition the Uganda Children's Statute (Organization of African Unity, 1999) set out to foster the community based care of orphans and specifically support child-headed households and children as caregivers. It advocates the provisional care of orphans within their extended families and communities by focusing on strengthening their capacity to support each other. The Children's Statute also stresses that young people should be fully involved in solutions to issues affecting their lives. This collective legislation sets the foundation for support, however limited, to children in need in Uganda.

In addition, the Children on the Brink Report, that came out in 2002 as a collaborative effort between the Joint United Nations Program on HIV/AIDS (UNAIDS), the United Nations Children's Fund (UNICEF), and the United States Agency for International Development (USAID), made five suggestions to improve the welfare of orphans. It is suggested in this report that focusing on strengthening and supporting the capacity of families to support their own children, mobilizing and strengthening community based responses, strengthening the capacity of children and young people to meet their own needs, raising awareness, and ensuring government policies that protect the children are all key factors in dealing with the orphan population. It is evident that there is mutual agreement that building and strengthening community is considered critical by the government and the NGO's active in the country. However the next step in confronting the massive problem facing these children is how to mobilize for the appropriate supports to be put in place.

A limited number of programs are specifically focused on aiding child-headed or young carer households in Uganda. In South-western Uganda, the Lutheran World

Federation Department for World Service provides support to approximately 200 child-headed households in the form of awareness education and counselling services (Lutheran World Federation, 2008). Mosaic Vision, another organization in Uganda, provides caregivers to child-headed households (Mosaic Vision, 2008). Their aim is to bring childhood back to the children by supporting up to ten orphaned children to live with an adult caregiver in a home in the community. Similarly, the Uganda Orphans Rural Development Programme (UORDP) promotes care and support to families and communities of orphans by supporting education, increasing food production through the adoption of appropriate sustainable and environmentally sound farming methods, community based health care systems, income generating projects, and school feeding programs (UORDP, 2008). In addition, the African Medical and Research Foundation (AMREF) of Canada specifically looks at linking female and child headed households, as well as community support groups for guardians of AIDS orphans, to health and social services (AMREF, 2008). Apart from these programs, some child-headed households receive support from community based organizations that are set up to aid all orphans in their area. The problem is that these supports are not widely accessible to the large number of children that may need the services.

Child fostering has traditionally been a commonly accepted practice in Africa, sometimes occurring to simply help out parents during stressful times (UNICEF, 2003). However, the number of orphans is significantly increasing due to the enormity of the HIV/AIDS pandemic. The Children on the Brink Report (2002) estimates that by the year 2010, 3.5 million children in Uganda will be orphaned by AIDS. Long term solutions will have to be put in place for these children because the proportion of orphans

will remain high to the 2030's, even if the rates of new infections were to level off in the near future (Foster & Williamson, 2000). With the high numbers of HIV/AIDS related deaths combined with the increase in orphans, the ability of communities to provide appropriate supports is coming under significant pressure (Drew, Makufa, & Foster, 1998; UNICEF, 2003). Orphanages are not economically sustainable nor are there enough foster care placements to support the number of children left without parents (Children on the Brink Study, 2002).

Foster, Makufa, Drew and Kralovec (1997) found that the three main reasons for child-headed households, as opposed to the children being taken in by their extended families, is that there were no known relatives, relatives did not want to move in with the children or relatives did not want the child to move in with them. Twelve percent of parents surveyed in one study in South Africa were unable to name a person to care for their children if they suddenly were unable to (Nkomo & Freeman, 2006). Nkomo and Freeman (2006) also found that even if parents found someone willing to take on that caring role, it might not always occur because of the multiple stressors involved in this commitment. This would lead me to believe that if the children coming from these families were orphaned, they would eventually become child-headed households surviving on their own. Foster (2000) asserts that the increase in the frequency of child-headed households is indicative of the weakening of the extended family and community safety net.

There is limited research on the children who are heads-of-households despite a growing population. The research that has been conducted has focused on a broader overview of the issue without fully examining the essence of the experience the children

are having in this role. Existing research does not tend to examine how children are dealing with these situations in their daily lives or how these situations may affect their future development. As such, Kellet (2004) stresses “studies in these fields have tended to omit the accounts of children themselves” (pg. 2). The few studies that have been conducted have shown that these children they are at a higher risk for depression, anxiety, and the consequences of a lengthy grieving process as they are continually surrounded by a dying population (Atwine, Cantor-Graae & Bajunirwe, 2005; Foster, 2002).

Due to the lack of research on the children in Africa I have drawn on the work conducted in Europe and North America on young carers (Aldridge & Becker, 1999; Aldridge, 2006; Cree, 2003; Godsall, Jurkovic, Emshoff, Anderson & Stanwyck, 2004; Dearden, Becker & Aldridge, 1994). This is not ideal because of the potential cultural differences in play. Differences exist in the types of skills children are taught, in what families and communities are experiencing on a daily basis, and the types of support networks that are surrounding the children. However, I believe that despite my caution, I have gained some insight into the phenomenon by looking at the young carer literature. Studies in Europe have found that young carers are not inevitably at risk of harm as a result of taking on this caring role (Aldridge, 2006). Part of the natural developmental process for a child is to increasingly want to contribute to their relationship with their parent as they develop an increasing capacity to help (Chase, 1999). If the child carer receives support, reciprocity, recognition and acknowledgement for their contribution to the family, they may derive self-worth from their role (Godsall et al., 2004).

However, they can experience detrimental effects if the extent of the responsibility they are faced with surpasses their level of maturity and understanding

(Aldridge & Becker, 1999; Aldridge, 2006). Godsall et al. (2004) also describe the role as being a destructive one if it inevitably interferes with the child's mastery of developmentally appropriate milestones. Or, as Cree (2003) found, the problems and worries that young carers experience increase with the length of time they have been caring. Without external support, the carer and the younger children are at risk for serious adjustment problems (O'Neil, 1985). Some also think that young carers have been emotionally and psychologically damaged (Siddall, 1994) or have lost their childhood altogether (Dearden, Becker & Aldridge, 1994).

Rationale for the Study

The purpose of this study is to understand the experiences of children caring for other children after being orphaned. I am trying to understand the ways in which this role has had an affect on their lives, and the ways they are coping with it, in order to discover the most effective means of support. The practice of children caring for children has been seen as a coping mechanism that orphans take on to deal with their situation (Foster et. al., 1997). It has also been seen as evidence that the traditional family and community safety net in Africa has weakened (Foster, 2000). Taking on the role of care giver allows them to remain with their siblings, to keep their house and land in the family, to remain in their community, and to be free from the possibility of being abused or mistreated by alternative caregivers.

It is evident that coping strategies are highly dependent on the specific situation and context. The multiple bereavements that child headed households are accustomed to is quite specific to their situation, thus causing them to react and be affected in very unique ways. Connecting this with research from the Western world, Cree (2003) states

that problems in the lives of child carers will increase as the length of time they are in this caring role increases. If the children are unable to have their feelings and needs validated, the burdens may eventually wear on them. Also, experiencing the deaths of multiple friends and family members may have an affect on the child carer's ability to care for him/her self as well as his/her siblings.

The weakness of the current body of research on carers in Africa is that it does not discuss the experiences of the orphans and the issues that they have to deal with on a daily basis. To date, the research has examined the prevalence of these children and the reasons for their emergence, but it has not stopped to ask how these children are doing. Support has focused on getting the children adequate food, shelter and other basic necessities without emotionally supporting them through the after-effects of having lost their parents and at the same time having accepted the role of being a parent (Foster, 2000). Children are not supported as they are left grieving the loss of their loved ones. It has missed the emotional connection to the lives of these children which prevents us from knowing how they are coping and surviving with their situation. This in turn prevents us from knowing how to best meet their needs.

The following study focused on understanding the thoughts and feeling the child carers have on a daily basis, the support network (if any) surrounding them, and what motivates them to do what they are doing. I hope my findings will help set the stage for professionals in the field to provide services that the children need most. By listening to the voices of these children, we will better understand their situation so that we can support them in the most beneficial way.

The study also looks at how these children who are heading their households are dealing with the demands of daily life. Children who are orphaned have been found to have a higher level of depression, anxiety, and adjustment problems which have the potential to affect the willingness for alternative caregivers to care for them (Freeman, 2004). Wild (2001) also suggests issues such as social isolation, disrupted schooling, stigma, and uncertainty about the future as factors prevalent in the lives of children orphaned by the HIV/AIDS pandemic. Multiple occurrences of grief and loss in the lives of orphans may also put a definitive strain on their daily functioning (Wild, 2001). In addition, if they are dealing with physical illness along with the psychological trauma, their means of coping are even more under stress.

CHAPTER III

Method

Grounded Theory

At the core of my research lies a pragmatist assumption that knowledge is constantly being built upon and may change from one day to the next. My beliefs parallel those of Corbin and Strauss (2008), in that I see knowledge as being cumulative in that it leads to action and action allows for the creation of new knowledge in our continually changing world. I believe that what holds true for the young carers in Uganda presently, may not be the case in the future, but that the knowledge we gain from learning of their experiences will provide a basic starting point in years to come. Since the purpose of the research was to inquire into the personal experiences of young carers, I chose to inform the study by a grounded theory methodology. This methodology embraces the knowledge gained from each subjective experience, finding value in the constructions of the young carers. I relied on the participants' views of their situation to facilitate my understanding of their sense of the world around them. Based on my understanding, I was able to create a model depicting the actions and interactions within the categories. Ultimately I used this model to focus on the practical implications of the data as I understood it through my analysis as suggested by Creswell (2007). .

Since the study is informed by grounded theory, the sample size depended on reaching a point of theoretical saturation (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Theoretical sampling is the process of gathering pertinent data to develop the emerging theory. The data becomes saturated when no new properties emerge in the identified categories (Charmaz, 2006). Therefore, I determined the end-point of the data

collection when there was a great deal of overlap of ideas in the data I gathered from interviews with the participants and through ongoing analysis. This occurred when I stopped learning anything new and all the avenues of interest were covered. Given the scarcity of literature pertaining directly to these young people, I did not conduct a broader search into possible related areas until I did an initial analysis of my data. I let my analysis guide my literature search. This followed a more traditional grounded theory approach (Glasser & Strauss, 1967).

Research Questions

The purpose of this study was to understand the experiences of children caring for other children after being orphaned, the ways this role has had an affect on their lives and the ways in which they are coping with their situation. This allowed me to be able to develop a conceptualization about the affect this is having on their lives in order to suggest ways we can best support these children to cope with their situations and then to move successfully into adulthood. The research questions that evolve out of this are: What are the experiences of children caring for children after being orphaned? What is the affect on them as a result of this experience? How are they coping with this situation? What supports are needed to lessen the negative and increase the positive affects (if any) it has on their lives?

Selection and Recruitment

As mentioned, Uganda was chosen as the site of the research because I was able to make contact in the country with an individual who is interested in my research area. Dr. Doris Kakuru, a professor in the Sociology Department at Makerere University in Uganda's capital city, Kampala, was crucial in the beginning stages in connecting me

with a local leader that granted me access into one community with known child-headed households in the city. She also helped me develop a strategy for contacting other communities. At her suggestion I conducted an electronic mail-out to a number of organizations working with children in Uganda that I could use as third party recruiters.

The other locations were chosen because individuals in different organizations responded to my mass e-mails presenting the study. The smaller community based organizations showed the most interest and were very helpful in providing me with information about the communities of children within which they worked. Once contact (via e-mail or a phone call) was made by these individuals I set up a meeting time to discuss the project further and decide on a plan. During this meeting I was able to thoroughly discuss the study with the third party recruiters. Once I learned about the work that was happening within their organization and how the study would fit with them, we discussed their role in the study, issues of confidentiality and the rights of the participants. The third party recruiters would then take some time to look at which children would fit with the criteria while I became acquainted with the community. During this period I spent time attending community events, visiting other organizations that were supporting children, volunteering at orphanages in the area, going to the markets, walking the streets, and having conversations and meals with people to get acquainted with the area and learn about their culture.

The potential participant children were all told of the study by the third party recruiter before even seeing me. However, in each area, the way in which I went to see each family was different. When the households were unmarked in very rural villages on unmarked streets, I was forced to travel to the home with the third party recruiter who

knew where the household was. Although the children had already shown interest and knew that we were coming, I always provided alternative options for our visit. I left it up to the young person how he/she wanted to spend our time together if he/she still wanted to spend time with me. I suggested ideas for us to share a meal together, cook, go for a walk, draw, or talk about other things. Often these activities were engaged in while I was at the house, and they intermixed with the interview. This process occurred in Jinja, Rakai, and one part of Kampala.

Alternatively, in both areas in Gulu and one part of Kampala, the third party recruiter would go to the young person's house and tell them of the study. The young people were then invited to come to see me at a certain location if they were interested in participating in the study. When the young people did come to see me, we would discuss the letter of informed consent and then if they were still interested we would make a time for the interview. The young people were given the letter and told that when I came for the interview we would sign it, thus allowing them further time to think about it on their own. On the day of the interview I would meet the household head at a convenient place for both of us and he/she would take me to his/her home. Each household head was visited only one time as per guidelines suggested by the Behavioural Research Board (BREB) at UBC. These guidelines were set up with the belief that a single visit with a child head would limit the potential distress the interview may cause and limit the affect the research would have on their day to day life.

I conducted interviews with 34 young carers in the four different districts. Of those that participated, 17 were male and 17 female. All participants began their role between the ages of six and 19 years, however at the point of each interview, they were

all between the ages of 12-25. The time they had all been in the caring role varied with each household head, from one to 14 years. The household head in nine households was not the eldest child in the family. The number of children in the homes ranged from one to eight. All but one household head had some schooling, and 11 young carers reported moving districts in their lives. The cause of death of the parents of the young carers varied although all but three were due to sickness, murder by the rebels, or a car accident. One father fled the home after the death of their mother, and the cause of parental death in two families was unknown.

Eight translators were used for 13 interviews because these young people felt more comfortable speaking in their tribal language. If a translator was required, then I left it to the young carer to decide who he/she was comfortable with as the person translating for them. The translators were community members, friends, or someone from a community organization. The translators were found in the communities by the third party recruiters or by the young carers themselves and changed depending on the household and the area. None were paid for their assistance. For a full description of the study participants refer to the chart below.

Table 1 Participant Demographics

| | <i>children in home</i> | <i>age at onset</i> | <i>Age Of HH</i> | <i>cause of death</i> | <i>gender of HH</i> | <i>time HH (yrs)</i> | <i>present schooling</i> | <i>HH oldest</i> | <i>Use of translator</i> |
|-----------|-------------------------|---------------------|------------------|-----------------------|---------------------|----------------------|--------------------------|------------------|--------------------------|
| 1 | 4 | 11 | 19 | Unknown | male | 8 | S6 | yes | no |
| 2 | 4 | 13 | 18 | AIDS | female | 5 | S6 | no | no |
| 3 | 6 | 18 | 22 | sickness | female | 4 | S5 | yes | no |
| 4 | 6 | 19 | 23 | AIDS | male | 4 | S4 | yes | no |
| 5 | 7 | 12 | 16 | rebels/ sickness | male | 4 | P6 | yes | no |
| 6 | 4 | 15 | 16 | AIDS | male | 1 | small | yes | yes |
| 7 | 8 | 16 | 24 | sickness | male | 8 | S4 | yes | no |
| 8 | 6 | 15 | 17 | rebels/ accident | female | 2 | S4 | yes | no |
| 9 | 4 | 17 | 18 | AIDS | male | 1 | S6 | no | no |
| 10 | 4 | 17 | 18 | AIDS | male | 1 | S4 | yes | no |
| 11 | 8 | 10 | 15 | Sickness | male | 5 | S2 | yes | no |
| 12 | 8 | 16 | 17 | when pregnant | female | 1 | S2 | no | no |
| 13 | 7 | 9 | 23 | rebels/ TB | female | 14 | none | yes | no |
| 14 | 5 | 11 | 21 | killed by rebels | male | 10 | 2 yrs Voc. | no | no |
| 15 | 1 | 10 | 18 | Sickness | male | 8 | P7 | no | yes |
| 16 | 3 | 14 | 17 | Sickness | female | 3 | P5 | no | yes |
| 17 | 4 | 7 | 16 | Sickness | male | 9 | P7 | yes | yes |
| 18 | 4 | 14 | 17 | Sickness/ fled | male | 3 | P7 | yes | yes |
| 19 | 7 | 14 | 17 | Sickness | female | 3 | S4 | yes | no |
| 20 | 6 | 16 | 17 | killed by rebels | male | 1 | P6 | no | no |
| 21 | 3 | 11 | 16 | HIV/AIDS | male | 5 | P7 | yes | no |
| 22 | 2 | 13 | 15 | Unknown | male | 2 | P7 | yes | no |
| 23 | 4 | 11 | 16 | AIDS | female | 5 | S4 | yes | no |
| 24 | 2 | 6 | 12 | Sickness | female | 6 | P3 | yes | yes |
| 25 | 5 | 13 | 15 | Sickness | female | 2 | S2 | yes | partial |
| 26 | 3 | 13 | 15 | Sickness | female | 2 | P5 | yes | Yes |
| 27 | 6 | 15 | 16 | sickness | female | 1 | T3- tailor | yes | Yes |
| 28 | 5 | 14 | 19 | AIDS | female | 5 | T3 | no | No |
| 29 | 4 | 10 | 17 | Sickness | female | 7 | T2 | yes | Yes |
| 30 | 4 | 19 | 20 | AIDS | female | 1 | P6 | yes | Yes |
| 31 | 6 | 15 | 16 | Sickness | female | 1 | P7 | yes | Yes |
| 32 | 6 | 9 | 15 | Car Accident | female | 6 | P7 | no | Yes |
| 33 | 3 | 15 | 18 | rebels | male | 3 | S5 | yes | No |
| 34 | 5 | 15 | 17 | AIDS | male | 2 | S3 | yes | No |

(P= primary school level, S= secondary school level, T=technical school level)

Ethical Issues

Risk of Emotional Distress

There are a number of ethical issues that one has to be concerned with when interviewing children in other cultures on what can be difficult to discuss topics. Perhaps the biggest one though is creating emotional distress in the children. After her own experience conducting interviews with young carers in Zimbabwe, Robson (2001) suggested the following ways to minimize emotional distress during interviews. Among them are establishing a rapport through pre-interview visits, providing information about the study and requesting feedback and questions, obtaining fully informed consent from the children, after reminding them of their rights, and providing information on the types of questions that will be asked during the interview.

Throughout the process of data collection I pursued the above mentioned suggestions for each interview I held in order to limit the distress caused to the participant. During stressful times, when tears started to fall, I would take a break with the young person and we would turn the recorder off. Consequently I offered to erase anything they did not want on the tape, and we only turned it back on upon their suggestion. Only one instance occurred where a young carer asked to turn off the recorder in order to tell me something private. Noteworthy is that in my very first interview, the young boy said that he had experienced so much suffering that often it was too painful for him to talk or think about. But that day he felt, "talking is like crying", because he was able to get it out and in turn he felt better.

This study dealt with a sensitive topic and was emotionally distressing for many of the participants to talk about. The potential for risk, however, was also minimized by my

extensive interviewing experience, as I am a practicing social worker. I made sure that every possible attempt was made to minimize this risk. I checked in with the participants throughout the interviewing and data collection process to ensure that they were okay and wanted to continue talking with me. I also stressed to the participants that the interviews could be stopped at any time to continue at a later date, or not at all if they chose. During many interviews, we took a break from talking to share some food and then children would tell me when they were ready to begin again. The families were all reminded as well about whom they could turn to in their community for support after the interview was over. However, many of these young people have never shared their experiences with anyone and they expressed gratitude about the experience when we were done.

I just want to tell people like you, maybe who come and do some research about people like us... its very hard to what? To get somebody like you to come and do some research, to know about our ways of living, just to know about us...its really hard, we have been living here for almost 6 years since our parents died, no one's ever come and just like this, maybe can I do this to help you or what... but I would just like to thank you.

The Rights of the Child

A multileveled consent process that had been approved by the Government of Uganda and the BREB at the University of British Columbia occurred with each household I visited (refer to Appendix II). The Uganda National Council for Science and Technology (UNCST) approved the study on the national level (refer to Appendix IIIa). They also approved me separately for each of the four districts I conducted research in (refer to Appendix IIIb/c). On a local level, entrance into the communities was generated by

community leaders and community based organizations in the areas. These local heads helped me get word of the research to the household heads. It was left up to the household heads to choose to participate or not. Each young person over the age of 12 in each household who spoke with me during my visit was fully informed about the purpose of the visit, agreed to participate, and gave written consent (refer to Appendix IV). When a translator was present, he or she also signed the form to validate the child's signature. The household heads chose where we sat to talk. Some wanted to sit outside not caring about neighbourhood children standing and watching off in the distance. Others wanted to sit inside closed in for no-one to see. They were able to choose where they were most comfortable. Also, on a few occasions, the household heads walked me through their house, around their land, or through the community explaining a bit about their culture and their community. This was something they chose to do.

On two occasions, both in different areas in Gulu, household heads initially approached me with interest but when told more about the study they changed their minds and decided they were not ready to talk. Both were thanked for taking the time to come and were validated and reminded that it was okay to choose not to talk and that nobody would be mad at them. Also, on two occasions, young people were keen to participate yet they had to be turned away because they were living with relatives. Also, one young carer household was living in a very unsafe environment and requested my accompaniment to speak to a local community member who was able to assist them to alter their situation.

Offering Remuneration

Remuneration for participating in the study was not discussed with the young people until after I had gathered the data thus preventing them from participating solely for remuneration. Remuneration was not pre-determined; it was something that the participant and I determined together would be the best usage for the monetary value.

Upon the suggestion of a community member, I always entered a household with food items appropriate for the time of day at which I entered the residence. In Ugandan culture it is customary for a host to cook food and share it with the visitor. Therefore, the young people often turned around and put the food I brought right back in front of me. Otherwise, if the household had the means to buy food before I arrived, they would have already begun preparing food for us to share. Therefore, my original plan of spending time preparing food with each family did not ever occur because the young people did not feel they were being a good host if I helped them prepare food. For the first three interviews, I accompanied the household heads to the market where we picked out a number of basic necessities for remuneration. However, I recognized that I was generating too much attention for these households upon doing that so if food was what they needed most the household head and I would write a list and send a younger sibling to the market with money to retrieve the items. Some household heads needed school fees, money for rent, or money for health related requirements. In these situations, the children were given the money to put towards these necessities. Ultimately I decided that they were mature enough to decide themselves where the money would be most useful.

Social Work Values

As a practicing social worker I am guided by my Code of Ethics. At the core of my research, I kept the best interest of each participant paramount. Although I do benefit by attaining a degree as a result of conducting this research my interest in the topic was not for personal gain. I did not exploit the participants. I fully informed them of their rights and the purpose of the study, giving them numerous opportunities to choose not to participate. I also told them I was not there to help but rather to learn so that support could be more conducive to the needs of child-headed households in the future. I continue to believe that the information gathered will influence service delivery for this population of children in the future. However, I cannot guarantee that the specific children who were interviewed will benefit from the findings any time soon.

I worked hard to respect the confidentiality of all participants. In each household we discussed ideas of what they could say to people who asked why I visited. Also, if people asked me about my study, I responded in very general ways and did not disclose any identifying information of those participating. I maintained participant confidentiality by keeping my voice recorder and data files with me at all times, unless I placed them in a securely locked room where I was staying.

Maintaining confidentiality during the research phase of the study was difficult. Organizations that put me in touch with the young people wanted feedback immediately and had trouble understanding why I would not regurgitate what the young carer expressed to me. I also had many discussions with the participants about why I would not take a picture with them in it. This issue falls hand in hand with child rights because children in Uganda are taught to both respect and respond to the wishes of adults.

Therefore, I presume many of them felt as though they had to tell an adult of the study just because the adult wanted to know even though I reminded them of their right not to tell others about their participation in it.

Also, since I am white-skinned I attracted a lot of unwanted attention especially when entering isolated rural villages. I attempted to be discrete but I was unable to prevent people from seeing me visit certain households. One family specifically expressed their difficulties with neighbours who were jealous of them having visitors. They lived in a rural village where white people were seen sporadically, along with automobiles, so when a car drove through the area with a white person in it and parked at their house, they worried that many people around them would start talking. They suggested leaving the car at the market and coming quietly so as not to attract attention in the future. This was helpful advice and aided me in being more aware of being as discrete as possible in future interviews even though I could not change the colour of my skin.

Data Collection and Analysis

As I was employing research strategies informed by grounded theory methodology, I was simultaneously involved in both the data collection and analysis. Individual, in-depth, semi-structured interviews with the child caregivers, was the primary method of data collection. This allowed me to understand their perspectives and to get a description of their experiences of being a young person who cares. One interview was conducted with each household head and any of their siblings who were over 12 who wanted to take part. The interviews themselves lasted between 30 minutes to two hours. However, the time I spent with each family ranged from one to four hours in length. I began each interview with an identified set of questions that I used to guide the

process to promote the sharing of information (refer to Appendix Va). Since I was only able to see each household head once, I continued to ask for clarification of the ideas that the participants presented during the interviews by reflecting back what I had heard and asking for their confirmation. I continued to interview young carers and their willing siblings until the data were saturated and I was not hearing any new information. The interview portion was audio recorded. I also took brief field notes on my thoughts and participant reactions and emotions during the interview. This served to spark my memory of events and activities that could not be caught on tape while transcribing. Following each interview I did a mini analysis, often listening to portions of the recording, in order to add, remove, or alter the probe questions because of emerging themes (refer to Appendix Vb). Once all the interviews were complete, I transcribed the data verbatim and continued with a more in-depth analysis.

I also obtained basic demographic and socio-demographic information about the communities and the child-headed households that participated in the study. Initial contact and observations of daily practices of young people in the communities occurred before the interviews took place. If a translator was required then I left it to the young carer to decide who he/she was comfortable with translating for them. He/she gave permission to have that person present during the interview. The translators all signed a letter of confidentiality before their assistance was used for the study (refer to Appendix VI). The translators were found in the communities and changed depending on the household and the area. All interviews took place at the participant's homes, allowing me to see their life story in context, providing me with a much richer idea of the situation.

As mentioned, my study was informed by grounded theory. This qualitative research method is designed to aid in the systematic collection and analysis of the data and the construction of a theoretical model (Creswell, 2007). The model that emerged from the data is my interpretation of the affect that caring has on the young carers as perceived by them. The emerging theory reflects my own values and worldview. It is based on my interactions with the participants and the communities of individuals within Jinja, Gulu, Kampala and Rakai districts that I spent time with while collecting and analyzing the data. This follows more of a constructivist viewpoint that as the researcher I construct the knowledge that resonated with me from the knowledge that the child carers construct from their experiences (Corbin and Strauss, 2008).

In recognition that my worldview was able to effect the data collection and analysis, I kept a journal throughout the study in which I documented my thoughts and feelings. Often I was quite affected by the stories the children were telling me. When they cried, I would turn off the tape recorder and sit and cry along side them. Since many had never shared their experiences before, their pain and vulnerability came to the surface in a very intense way. I felt their raw emotions in a way that I did not prepare myself for. I reacted to their stories at the level they were at as their emotions emerged. This in turn provoked them to open up more and more to me. Therefore, there were times when we connected at a very deep level and I felt that I had to switch roles almost and go back to being a social worker. I found that there were some thoughts and feelings that the young people shared that I should not probe further as I was unable to devote the time to these that they deserved. Rather I connected these young people with support in their community. These were the periods at which I turned off the recorder and dealt with

these issues of safety. My main concern throughout all of this was to uphold the best interest of the young carers as my most paramount concern and I believe I acted accordingly. As a result of all of this, I needed a way to gather my thoughts, compose my feelings and release my frustrations. The journal acted as my release and personal reflection, allowing me to note my thoughts and reactions at the time of my data collection. By conducting the deeper analysis back in Canada I had time to separate myself from these subjective feelings and reactions that I was immersed in while living in Uganda. In my analysis I was able to take a step back and look at what the children were telling me on a more objective note, without forgetting those thoughts and feelings of mine at the time and using them as a key piece of the puzzle.

I was unable to transcribe the interviews in Uganda due to a lack of time, as I was only in Uganda for a short period. Therefore my initial analysis took a different form as I alternatively listened to the voice recording and noted my thoughts about the meeting within an hour after each interview. This allowed me to look at themes that emerged and needed clarification so that I could accordingly alter my interview guide with new questions. I began transcribing the recorded data verbatim once all of the interviews were conducted and I returned to Canada. As soon as the transcriptions were completed I was able to code them inductively using all the notes I had gathered while listening to the voice recordings, transcribing each interview, and then reading the transcribed pieces. My attempt in analysis was to stay as close as I could to the data, therefore I often used in-vivo codes and themes to represent the experiences the children were expressing.

I created the codes based on what emerged in the data, and influenced by what I saw. According to Glaser (1978), the first grounded theory mandate is paying close

attention to coding, which I was able to do by stepping back and looking at the big picture of what the data was telling me. I continually read and rearranged codes, starting off very descriptive but over time moving to a more theoretical level. I looked at continually defining the codes and refining them throughout the process to try to understand the participant's views and actions from their perspectives. The initial evolving theories grew as I listened to the stories of the participants. After transcribing all of the interviews, I read through each one jotting down key themes that emerged. I combined them into a list which I used to begin a more in-depth piece by piece coding of each interview. During this process I was continuously comparing, removing, altering, adding, and combining codes as categories emerged, consistent with a constant comparative method of data analysis. The themes were then grouped into larger categories which highlighted six key categories of interest. My memo-writing throughout the analysis documented the dimensions of each category enabling the construction of a model to explain this new knowledge.

CHAPTER IV

Findings

In this section, I will present the views of the participants as I have interpreted them from our discussions together. I have chosen one of many quotes to represent each piece of the six themes that have been identified, in order to tell the story of the lives of these child headed households in Uganda. I will start by explaining their experiences of loss, the reactions they had, the support they receive in the community, the vulnerability they experience, their ways of coping, followed by their acceptance of the situation, and finally ending with their hope for the future.

Theme One: Loss

As I have mentioned, Uganda has been plagued for many years by civil unrest, AIDS, other communicable diseases, and high accident rates- all contributing to death. Each child-headed household I visited had some story of the loss that they had experienced in their short lives. According to one girl:

In Uganda here we have a problem... the parents cannot stay for a long time... they can die...

If the deaths were not sudden, many of the young people ended up caring for sick parents anywhere from a couple of days to a couple of years in length. For many of them, this marked the beginning of their role change.

And even when our father was there even we were the first cause we dig, then we cater for them cause all of them they are sick. At times they rushed them to the hospital, I myself I am to take them the food, doing the washing the clothes... and

caring for my mother was really difficult, cause I am alone and these children they are still young, even I too. So catering for her it was even very difficult.

All but one young person lost both of their parents to death. The remaining one had their mother die and a year later their father said he was going to work but he never returned. In this section, I will present the participants experiences with loss, beginning with the most prevalent cause of death, sickness, to the least reported cause, car accidents, among the 34 young carers.

They Fell Sick and Died

Many of the children experienced a loss of their parents due to AIDS, malaria, tuberculosis, meningitis, sickness during pregnancy, and some other unknown (or not discussed) sicknesses. As vocalized by one translator:

About her father...The sickness that give him headache, after that, he was taken to hospital, and then they came back with him and then they died.... About her mother, begin as a similar problem, she was taken to hospital, she stayed there for a long time, after that they took her back, and then again they took her to hospital and then she died from there, and then they took the dead here and then they buried.

The Rebels Killed All of Them

The second most commonly reported death of the parents was as a result of the war. These deaths were often sudden and involved both parents concurrently. When the rebels were in Gulu district, many parents would try to protect their children by sending them to hide away at night. One girl reported:

So at night for us children, the young children like this, they send us that you go and sleep in the mission because the mission is quite protected. You know, they felt that those people would come and attack children sleeping and turn them straight into soldiers. So they used to tell us to come sleep in the missions' home. However, in the morning when the young people returned to their homes, they had no idea what to expect. One young carer reported:

I remember...in the morning I came back home and I find nobody home, I asked somebody about my parents, they tell me my parents were arrested by the LRA, when I was still young.

Not all the raids in the north occurred at night. Some young people had their parents stripped from them and taken by the rebels during the day, even if they were at a protected camp. The parents were trying to protect their kids from being taken as soldiers, but hiding the whereabouts of the children in turn caused the LRA to kill many parents.

That was in 2004 when the LRA rebels come into our camp... in our camp then they raided us, that is when my father was killed, and my mom, and so that day we had nowhere to go, we were even young.

They Got in an Accident and Died

Automobile accidents were also a cause of sudden and unexpected death in some child-headed families interviewed. Often the accident occurred when the family was trying to move to a safer location. The parents would take the first step and leave the children for a short period to get things settled before calling for them to follow. The loss often came as quite a shock to the young people who were planning for some other life-changing transition to take place.

Then in 2006, at the end of the year, my mother said that we can no longer stay here because we don't have any power, like there is nothing for survival, the standard is so poor, so we could not afford now, so we should go back and dig in the village, so she said let me first see whether we can get somewhere to settle, since people are now going back to the camp. Then she said we should remain here, she is just going alone. Then she come and maybe pick us from here. Then the way going she got in an accident again. Then they took her to the hospital, of course there were like ten people who got in an accident. They took them to Lira hospital, for her, and maybe two people, they died, after three days, they died.

Loss was identified by each household. It is the core piece that results in these children being orphaned, but it does not result in them being child-headed households. That comes from within them. I will now describe the reactions the children have to this loss.

Theme Two: Reactions

Even if the young people were caring for sick parents, they reported that it was still better when their parents were at least there. At least then they had someone to turn to for support of sorts. The mere presence of the parents provided them with more of a sense of security. Even if they were struggling before, at least they were struggling together.

Though the mom was there- he could bring that thing and the mom was there, but now the mom is not there, he is the very person to go and look for the thing and then to come and prepare it.

In this section, I will present the reactions of the participants to the loss of their parents followed by the reactions of the community through their support to the households.

Reactions of Self

The children reported this ongoing experience with their parents through the thoughts and feelings that continued to engulf them after their loss.

I remember it was good

The most common memories the children had were of better times with their parents. No matter how much they suffered and struggled to get by with their parents, it was even worse without them. One child said:

But what can I remember in my life is good... is only when my parents are still alive.

We would not be in trouble

With two parents working, the participants reported at least achieving a balance in their lives. They ate, they slept, and they were able to play with their friends. The worries and the hardships for the most part were left for the parents to deal with. Again they remember the time with their parents as the better time. No matter what was happening then it was not as bad as what they were experiencing now.

Our life would be different... if our parents were there we would then not be in this situation, because both they work for money, everyday my mom sells fish and they pay her money, at least we can achieve balance when she was there we can eat good things, and now, nothing....

When they died everything changed

When their parents died, the burden of money, food, shelter, clothing, and health care all fell on the household head. These children had to start thinking of everything, taking on the role of both parents. Their childhood disappeared and they were forced to grow up fast.

‘Cause life changed, ‘cause we used to not live in such bad situations maybe... cause our parents loved us so much, at least they provide us, at least with everything they could do... everything they could they would give us, but ever since they died, especially my mom by the time she died life changed totally.

Memories of the parents providing for the children were most common. They remember having all of those basic necessities even if it was a struggle to get them. The difference was that before it was the parents who would struggle to get them. Now they had to take over. The struggle was left to them.

What can I do

The young carers reported that they constantly questioned their situation. This was the first time that they were left to make all the decisions with no guidance from anyone. It was almost as though it was the beginning of them trusting themselves as being okay to make decisions and take control of the situation, even though they knew they were doing all they could do. One young carer reported:

And that time my mom was not there, oh, I start crying... what can I do? My mom is already died... was already died... what can I do?

We were left with nothing

Even if the parents were sick for a long time, plans for the future were not made. Some families were left with a shelter that was owned and crops to continue digging. But for most of these families living in absolute poverty was a reality. Their parents were already scrounging for money to buy food and other basic necessities on a daily basis, so upon their death there was no safety net to pass on. As one translator said:

After the death of her father, she stopped schooling because of very many things, she lose, she don't have way to get it...

Why I don't understand

Some participants felt that they were being punished. They would look around and wonder why God chose them to be in this situation and not their neighbour. They would wonder what they did wrong and why they were being targeted. Life for many of them was already hard enough so this adding to their struggle was unimaginable.

Cause at times [I] may have said oh, my God, why me? Why us? When I tell you I fail to sleep... you can fail to sleep thinking of many things... oh my God, if this God can answer our prayers like think like that...

Crying

Many expressed this emotional reaction to the stressors they were experiencing. It would most notably occur right after the death of their parents. It was a grieving reaction coupled with the realization that they were now in charge and had to do something.

I was young, so the only thing I have to do is only crying... those aunties of ours she used to tell us that you just make fine, your mom will come back - and yet things will not come back.

Some also admitted that they would often cry when they were alone. However, that it was something that they tried to hide from their siblings because it showed a sign of weakness. Now that they were the mature ones they were not supposed to be the ones to cry.

We used to be free like other people, but now you are alone in the house, no mother, no father, like that. So you think, that thing comes back in your mind, you start thinking, and you can even end up crying. Alone in the house... sometimes these people can ask me that what are you crying. But you know as you are big you can't tell them. They just see you crying, because you are having that memory.

One family openly discussed their decision to not tell their youngest brother that their parents had died. They continued to tell him that their parents went away to work and that they will be back. They feared that too much crying would make him sick, and they felt helpless when he cried because they could do nothing to stop it.

Now... at this time... he will think... he will not feel good when we tell him that they died... he may cry... and that's why we fear tell him...crying through the night and may be become sick... but he goes ahead and crying... may be up until when he sleeps.

Deep thinking

Along with crying, deep thoughts troubled the household heads. Any sort of thinking was thought of as difficult. Thoughts of the past made them miss what they had, while thoughts of the future added to the pressure that they were feeling on a daily basis. One translator reported that:

Sometimes, if she goes to easy life it mean that she is not thinking a lot, that sometime when she is in a difficult life, it means she is thinking a lot.

These feelings ranged from those of loneliness, to worry, to sadness and fear, to a deep sense of sorrow about their loss, all the way to suicidal ideation.

Alone/isolated/lonely. None of the young people reported ever wanting to be alone. Being alone just brought thoughts and feelings that they did not know how to handle.

We were thinking that we are now alone... we are suffering, we are going to suffer... because when she was there she was telling us that when she is alive we should not suffer...now when she died...now we were thinking that we are now left alone, we cannot do anything.

However, sometimes when they were with other people they felt like they did not belong and that sometimes made them shy away from others that they used to be comfortable around. One participant said:

I feel like we are isolated, like we are a different kind of people that nobody wants. That is how I feel.

Worry. The thoughts of worry often never left their minds. There was always something to think about and nothing was ever certain. Each day was already a struggle.

In addition they worried about something else going wrong and that something would happen to add to their struggle. The young carers had trouble concentrating when at school. They were constantly thinking of more pressing needs in their lives. As one translator described:

She feels very sorry to leave these kids alone at home because she is the one needing them, now. If she went somewhere to do something, she just maybe for example, if she's in the class her mind keep quiet. Even though the teacher is asking her- can you please give us an example of physical feature of east Africa...then her mind keep quiet... she just see the teacher as if she is now mad... they keep on asking her, and they chase you away from the class because you are not giving me the answer, yet their mind is now quiet. She just keep on shedding tears, because of her fellow sisters. She just keep thinking about if they are going to cook or if they are waiting for her.

Sadness. For many, sadness defined their current life. The sadness most often began at the point when their parents died.

Very sad....when my mom is not there. A sad day....there everything I remember...the sad day...it was February, when father passed away, I fainted from school because I never...because he got an accident, he was going to Kampala to collect our fees, then he got an accident, and he was unconscious. I went to Lacor [outside of Gulu town] hospital to see him, I found him unconscious completely, he cannot open his eyes, he cannot shift his body even...that was a sad day I can remember...up to now....

There was also sadness felt as a result of a lack of option about what to do. During the times when they were struggling the most the thoughts of their parents rushed in and they were reminded of what they used to have. Nonetheless, many children also felt sad when they were unable to provide for their siblings like their parents would have done.

When asked to describe the sadness, one translator replied:

Yes, he is not happy...because if he come back from school, if you reach home, looking small kids, it is not good because there is nothing for them to eat... they are so sad.

Scared/ fear. Fear was commonplace. The young people knew that there was no one around them that was going to protect them as their parents did. Fear was evident for many reasons. This included fear for the future, fear of being vulnerable (to thieves and rapists), fear of being alone, and a fear of not ever being able to get rid of the thoughts in their heads. One young carer felt:

The last time I got scared...I'm almost every day I got scared.

Deep sorrow. Many young carers discussed feelings of deep sorrow which often occurred directly after their parents' death. When interviewing one girl, a translator said:

She feel deep sorrow at that time, because she was going to live lonely without any parents.

This extreme and intense feeling was so strong that none of them wanted to feel it again; however, it emerged when thoughts or discussions about their parents occurred.

The young people tried to prevent its presence in their lives by keeping quiet. One young female felt that she could not talk to anyone about her life because it would result in her feeling this deep sorrow. Another translator explained:

If they feel deep sorrow, [their grandmother] will advise them with how to live.

[They feel this deep sorrow when] they think about the loss of their parents

Suicidal thoughts. As I described above, the participants were experiencing quite powerful and often draining feelings throughout their daily lives. Five of the young carers specifically discussed suicidal thoughts that they had when they were feeling like it was too much to handle - taking pills, swallowing poison, hanging oneself. One boy felt:

Sometimes something comes and pulls right on my heart. Boy I hate living like that. Why don't you swallow medicine and die and follow them.

Reactions of the Community

The reactions of the community were evident by their various means of support. The household heads named numerous organizations they had been supported by or had some sort of contact with in their communities. These support organizations included the Federation for Education and Development, Hope Alive, Children of Grace, World Food Program, Meeting Point, Cooperaid, Rakai Area Counsellors Association (RACA), Send a Cow, and the Orphans Community Based Organization (OCBO). However, most of the support the child heads relied on came from individual people in their communities including neighbours, teachers, and personal friends. These were the people they most often turned to for support. One child head described how she often turned to her neighbours in times of need:

So maybe other people can maybe help you when you are in problem. They can bring you these.... Okay, you put these....they can bring like beans, eh, just like that, those people that are just good like that. That is how we are living, up to now we are still here.

They sometimes went to teachers when they were having trouble paying their school fees and needed some more time to make the money. One young carer in particular felt that her head teacher took extra special care of her. She said:

I have the person who holds me from school, the big headmistress who cares for me each and every time, looking after me, as I am her daughter...

They turned to friends when they did not want to be alone, as an escape, to borrow food, and when they were seeking advice.

We just talk about our future....even because for me I am suffering from typhoid...sometimes I will be very weak, yet from the dispensary school they are asking me to take a lot of juice yet I don't have any kind of it....then she take us and she gave me....she's ever looking after me and I am ever looking after her...

Advice from others

Community members were reported to offer advice to the child heads, and when they did not come to them on their own, the child heads would seek it out from them. One young person said:

Sometimes I go to the youth in our church and I present my problems to them... then they will give us some advice, then I will at least be relieved.

Some people advised them to be strong, as one boy reported:

I am a man and I had to stand like a man because people are advising me.

Others were advised to stay together and cooperate with each other, as one participant said:

Other friends give me advice- don't stay alone, keep on staying with your friends, keep on staying with people even though you don't like them, you just stay so that you get a happy life. Just like that.

Many community members also advised the young carers to do whatever they could to stay in school. As one girl reported:

I should not leave study, cause that one is the key to me and I am the one to open the ways to my young brother and sister. Now if I am to be big, then I will move all the future of these children. And they told me if I can concentrate on my books, then it will be better.

Still other members encouraged the child heads to continue with their lives, to never give up, and to push towards the future.

Like if I tell those problems to my friends they always encourage me – that is now how life is, you continue with it, in the future you make a goal what you wish to be, you will be it, you will live all those life, there is no permanent condition. That's what they usually advise me and they encourage me.

Some young carers recalled being advised by someone in their community to live safely, as one translator said;

They advise her to live safety together with these young kids, not to leave them; as leaving the young ones alone would put them all in further danger.

Support from extended family members

Each young carer reported a different relationship with his/her extended family. However, two categories emerged defining their experiences. The young people either had nobody around willing to help or they had someone near who would offer limited

support. Not one household was given unconditional support from any one in their family.

We do not have anybody willing to help. Many extended families reacted to the deaths by pushing the young orphans away. They simply had no resources themselves and were stretched thin, or they were sick and already struggled to care for themselves.

And there's no any person... Our grandfather told us that if we want to study we should struggle on our own. For him he has nothing and he is also sick.... Then there is no relative of which we have got....even if we go to them they will say that for us we don't have anything... now you stay as you are. Those who have not educated there are many, and if you want to be educated you look for your own way and you support yourself. And nowadays we are also surviving. We stay alone, even if they come... they met us on the way, they will not say anything. They will just say that for us even there is no money; there is not anything for which we can help you with.

They will help but there are limits. Other child-headed households received some support from their extended family; however, it was limited and did not cover all of their basic needs.

That aunt of ours was one.... They told us that that was our aunt, and we were staying with her together in that camp. So before she was also visiting us, and our father and our mother told us that was our aunt. And we really believe that was our aunt because she loves us. Sometimes if she comes she comes with bananas and gives us. And we know we really have her and that's she loves us. And after the death of our parents, she had a very hostile husband... she was only able to

rescue this child of ours-B. So she have to keep B with her up to last year. But we were quite older, but that husband cannot really accept that to keep all of us. And we say this is not our desire to be like this. Let us go and do our things out.

Others like us can support us

In the community, the young carers felt that it was easier to talk with someone who understood their situation and who was in the same situation as themselves. Often they would turn to their siblings because they knew they would understand their feeling better than someone not going through it. When asked who she would rather talk to one female head responded:

In position....in the position because somewhere like on the road is not good... you go to these children's homes, then you sit down, and then you start discussing that problem... yeah....

Religious support

Religion was important to many of the child-headed households. Some young people sought support in praying to God, while others would turn to pastors and church members when in need. Many of the community based organizations also had some sort of religious affiliation.

I always talk to many people like pastors... I explain myself to them...then they always give me the advice that I pray hard... I never know what will happen in the future and God will help me in future... that anything it is easier is better you suffer when you are still young. But in future, you be somebody responsible... 'cause you know what was happening, if I do this, I will not make it in future.

Then they sometimes they pray, sometimes they come and they visit me when I am in hard times.....and we stay like that one.

It's too difficult for me on own

Even though many of the participants recalled different levels of support in their community, many felt that caring was still too difficult for them to do on their own. Some children reported feeling very lonely. Some learned quickly that they could not depend on anyone outside their siblings and that made them feel very isolated. As one translator stated, “there’s nobody help her, herself alone”.

When there were options, or when someone was known to help, the carers reported knowing when they needed to go to someone and ask for help.

If I go to somebody, I ask for help... that one from there if I ask for somebody to give me help and she said oh, his or her, she said ok I have nothing to do from there I said ok no problem, if you get any time you can give me. That is how I tell them.

Barriers to receiving support

Since there were limits to support from people, the young carers were also weary of being a nuisance and wearing out a resource. Therefore, they would use certain resources and support networks only as a last resort. One translator understood:

That there’s no anybody that came out to give them services... its only she and if she has something to tell them or to give them, she is the only person.... They don’t go to Mamoyete, this lady who came here presently... but they go when they have seen that they cannot afford anything at all. If they go to her she can

either give them as maybe posho [staple starch food], she can give them like bean, she can give them like maybe money if she is having... but they don't go to her frequently.

The participants reported many things that prevented them from receiving supportive services. Many household heads also felt that they did not know about the services available to them or that the services were not accessible. Many also recalled having tried numerous times, as one girl stated:

I tried, was it last month, or last month but two, I tried a certain woman as they were writing some names of children there... I went to her... I told her if you can help me... then she said let me try... I will tell you [what] they reply. Then I went back to her [at] that home, [she said] the children they are enough, they have got enough children... then I said ahh anyways. I have been trying but you know people here they don't have the same heart.

Many of the young carers also felt as though they were not included in the support or that the support available only went to those with connections. As one young person said:

I think it's because of friend and relative... if they are told to come and pay the school fees of an orphan, they just write those children name, their relative children only. That makes me not to be helped by NGO's [non-governmental organizations] because I don't have anybody who can write my name.

A few of the household heads also recalled being promised support by friends of their parents, people in the community, or certain organizations, but never received anything.

Other people are the one to comfort us. Other people could come say, oh poor little children how will you live? That's the thing that I really remember. And other people could say I really feel pity for you. But they cannot give us anything. Because they were- people only say words, and then they don't give anything, just like you are chasing air. Then nobody said that we can stay with them then they simply said oh, you poor little children how will you live...so those things really stayed in my heart, then with some other things that we remained, we decided to leave there after...

Consequently, many ended up in a period of waiting. They were either waiting to hear back from an organization they signed up with or they were waiting for support from a member in the community. One young carer told me:

Sometimes they say we should wait...cause they don't have the things like at that time... so we wait...if they get they will bring it here.

However, all of these dilemmas the young people faced with getting support and with reading the reactions of members in their community made it difficult for them to know who to trust. Trust became an issue with many household heads. The participants learned that people lied to them and that they could not depend on anyone for anything. They learned to be very sceptical of people and services offering support. They learned to stand on their own knowing that the only thing in their lives that was constant was their siblings. Other people promised many things but would never follow through so they would not put their trust in them. Some of the participants also felt like they could not talk to those around them because they could not trust them to keep it to themselves. One young person stated:

Some people I don't trust them, they can tell everyone, but for me I just keep quiet, I don't tell them my history, background.

It is not enough

What was evident from the interviews was that when the children received support within their community, it was often not sufficient. The household heads found that there was always a limit.

Yeah, they say they are going to pay for us for three years, and they started paying for me when I was in senior one and this year I am in senior three and they are stopping this year. And I don't know where to go next year because I have to be a candidate [she had a test to take in order to move on to the higher level] next year.

One household head believed that no matter how much he was able to provide his siblings they would always want more because it is the natural human response to always be looking for something more. Therefore, he believed that no support would be able to satisfy their needs.

Though they will not help them to the satisfaction of them, but at least they would have done something good for them...not all their needs...he will be able to give them, though, it will not be that everything will be provided, but they will give them at least some help or anything...really for human beings, for them to have- they will aim at a certain thing when they start affording, they will start aiming at a another one. Now to fulfill their needs is very difficult.

Oftentimes, the participants felt as though they were left stranded or that they could not feel sure that the supports would always follow through.

There are some people they come here and they come that they are going to help us but we don't see any help. We just stay here. Someone just comes, 'You give me your name. You give me your reports.' You give him but he doesn't do anything.

Other participants talked about their experiences of people in the community getting tired of them. They were forced to continue to ask for help because their situation was not getting any better but this took a toll on the resources of the entire community.

One girl said:

You know, we used to go the other time. We didn't know that they are tired of us. But one neighbour told us, 'Ah, I'm tired.' Even me I have to cater for my family.

How I would do it

Although the reaction by the community is to come to the support of these young people, there are many reasons why the support is limited and/or hard to get. When asked, the participants came up with creative ways of how they would want to see support happening for young carers like themselves. One suggested finding the talents and strengths of individual children in order to build on them:

What I want to see happening is like everyone has to be kind of involved at least somewhere...with the people around them at least maybe, also be able to use some of their talents 'cause at least you know in talent someone is able to achieve. It's like a stepping stone, one's talent I mean, that's why most of the students with their parents fail to achieve because they don't see their talent... forgetting ... but at least for our kids here at least able to know that at least can able to play some

good trumpet..... which at least at any time can give me something good. So at least if it is to be there, he try hard to see that there's a way to test everyone around to see what he can do best.

One household head felt that an emphasis should be put on school fees and health care. She said:

What would you do... if they are sick or suffering from malaria, we would take them to the hospital and then advise them to go to school.

Another participant suggested that all of the orphans should gather together to form a discussion group.

A group of orphans... a group of orphans sitting together and discussing...like discussing about our life, how the life in future, how to make life in future, and also to advise each other, to get some ideas from other friends, from other people like that.

Many also felt as though they wanted to help others like them. Five of the household heads in particular wanted to make something of them in order to be able to help young people like themselves in the future. They wanted to stop others from suffering and since they knew their situation they felt they could offer advice and support.

My goals...I want to help other people, in case maybe when God helps my future....I also want to be helping others...like other children who are suffering, others who are in the street.... I want to be helping them, like the street children. I also want to maybe teach others.

Theme Three: Vulnerability

The household heads recalled facing many difficulties every day. Most felt that the biggest portion of their lives was spent dealing with challenges, while easy and enjoyable times only occurred sporadically, if at all. One young person believed:

The good part of my life... I don't see any good part of my life, because all the time I feel difficult. So you see there is no good part of my life.

The participants experienced many difficulties because they were so vulnerable for many different reasons. They were young, they were without parents, they were caring for numerous children younger than themselves, they were living in extreme material poverty, and they were lacking an education. This section outlines some of the vulnerabilities that the young people faced in their daily lives.

It is Always Hard

Our problem is not having our parents

They consider the fact that they had no parents their problem. They were children without parents who parent other children. One boy told me:

When there is hard days, [there's] no one to turn to. Because we are the child parents, we have no parents ourselves and a child as well.

There is always something to think about

The household heads found themselves always thinking about their siblings. They felt as though there was too much going on, too many things to think about. They worried about what they were going to eat, what their siblings were doing when they were not around, and they wondered about their future.

But we have a little difficulties here... 'cause at times they might come back, they might come back here, if there's no food, and it's you they have to look at you... you're not working...you hide... but you have to eat... no matter what you have to, what?.... you have to eat... and at times, you know cause they have gone to school.... They have done their part—I also have to do the part as a parent.

It's never a good time

Two of the young carers felt as though they had never experienced anything good in their lives. They felt as though it was difficult all the time and that nothing was ever easy for them. One translator reported:

He never had any good times in his life, because before he was younger, and by the time he could understand he was an orphan and he couldn't enjoy anything. But he doesn't have any earnings which can help him to have a good time.

I am not able to do what I want

The household heads gave up a lot and took on even more by parenting their siblings. Many wanted things for themselves that they had been unable to achieve as the bulk of their time was delegated to their caring role. One young person reported:

My life is very difficult because there are very many things I want to do and there's no way I can do.

We are different from others

The participants also felt as though they were living a separate life than other young people their age. They were acting as a parent but living in a child's body, thus preventing them from being able to connect on the same level with their age-mates.

‘Cause I think that it is.... Most of the 18 youth in Uganda they are still with their parental carers, they are still told what to do, where to go, how to eat, at least for these kids, I am just handling everything on my own...telling myself what to do, where to do, what to do and at what time to eat....

We are still young

The young carers talked about the loss of their childhood. They felt that they were “too young”, or had a “young brain”, or were not mature enough to be a parent and know what to do. They believed that being a child parent made everything seem difficult. One young boy suggested:

I know how difficult it is, to take care of the young children, yet you are also young.

I tried and I failed

Material poverty was commonplace among the child-headed households I interviewed. Since all of the young people were living day to day, some days they were unable to make ends meet and they felt as though they had failed.

And some other days, even you can’t even get a small job, even to get a single coin like 50, you can’t even get that one, I feel hard life from there, because I have no where... I am looking forward and backward. Nowhere I can go and pick this thing [get the basic necessities], that is some of the days I can feel hard life from there...yeah sometimes if I fail to get those things... I can come home and I tell my brothers, tell them that you see today I have failed to get this, so don’t mind.

Work related difficulties

All of the household heads report knowing that they have to work in order to survive but that it is a difficult thing to do being so young. One who went to work in a stone quarry to support his family stated:

So I think I can go and carry stones to change our life. That is the hardest part of my life, carrying the stones...”

There is a lot of pressure on them to make money. Those that are alone working have trouble dealing with seeing all the other young people their age going to school, as one boy reported:

During school days, if they are all to go, and me, to work alone is also difficult.

Inadequate Needs

We are lacking basic necessities

Proper shelter, school fees, food, water, and health care were all considered as basic necessities by the household heads. Not one household was able to achieve all of their basic necessities.

But in here how we live, we find the problem of eating, and the house... because some days- bugs...ok the house it falls down. And we don't have money to afford to build the house, because we are living in the slum areas, water can come. It can make it to fall any day because water enters and then the problem is school fees, eating, even when we are sick- we find the problem of going to the hospitals.

Because even the hospital they like money.

There is uncertainty in our day to day

Similarly, nothing was guaranteed. When it rained, the young people working in the stone quarry could not work because the stones would cut them and it was slippery. If they were having a drought or they were in between growing seasons, those participants digging for survival were without food. Jobs that young carers did for others requiring physical labour could be there one day and gone the next. The participants never knew what each day would bring

If there is no money, like now these days everything is expensive... we cannot eat only cassava which is in the garden, we can come and cook it then we sleep and tomorrow again that one we do. And life becomes very difficult. At times even affording salt to feed us we go and beg from the neighbours there and to the friends of our father. Then sometimes she will refuse and sometimes she will accept. And she will find that life is very difficult and if you are chased from the school and you know that you don't have money, it will be very difficult, cause the school they will not accept anybody to be in without payment.

We Are Not Safe

Many of the youngsters reported that they felt unsafe for many different reasons. They were taken advantage of, abused physically and emotionally, cheated, stolen from, and deceived.

He forced me

A number of the female heads were either pregnant at the time of the interview or had small children of their own. Rape of young women is common throughout Uganda. Although the government is trying to take measures to prevent the rapes, many young

girls, especially those living in rural areas, are vulnerable. One family of five (the four eldest being female) in a rural village in northern Uganda, reported that they knew which areas the boys would sit at and wait. Yet, they were forced to pass through these areas every day in order to go to school. They report being terrified and simply running as fast as they could to get away.

That there's a certain day they open that gate at around seven, and she was coming, there was a certain groups of boys who stay around near Awaranya [a small area in their village near Gulu town] there- [the] school, they group themselves into three groups, the first group will step on the way where people move and the other one will hide behind the latrine, and the other group will go up to the main road, and if you are coming, you have to run... because they will be waiting for you. If they catch you they have to rape you. And there's a certain day, they found her on the way, and they asked her [she told me the phrase in native language of Acholi]...what's your name... that you girl, what's your name? Then she just keep quiet. They started running after her, then she run so that she can run and enter inside. But she's feeling a lot of difficulties in it because that thing is giving her a hard life.

I thought she was a good person

Sometimes young people were sent to help out other families in times of need. Often the eldest child would go and live with an aunt or a step-mother to help take care of their children. Many times the young people found they were blindsided because they started off thinking that they were wanted for good reasons only to find out that they were being taken advantage of.

Then the step-mom, she came here kindly 'cause even I thought she's a good woman. She's going to cater for me but she came here, she asked because she was, by that time she was feeling alone. So her intention was just to get someone to, to keep her there... But when the children came back, 'cause others they were in boarding schools. But when they came back then she changed the mind because she had, because the children were back. Then she decided to say that you go back to your place.

I was deceived

Some of the young people reported being deceived. One was not paid for the work he had done over a two year period. His younger brother stated that:

He went somewhere, somebody came here and deceived him, he went with him to ask him, he have some job somewhere in Tororo [a central eastern district], so he work from there almost for some two years, and that person ate that money whole, and he came back without anything...

Another family felt deceived by an uncle who told them he would help them to take care of their father's assets but who stole it all from them instead.

Yeah, the thing that got us here, you know when we lost our parents, from there, there was an uncle of ours who came and deceived this brother of mine the eldest brother of this one, and from there the uncle told us that ok you know when your dad was alive, he told me that I'm going to take control of you, all of you, and this thing I'm going to handle.... So from there he took everything from the house, in the house, and he demand just like that without anything.

A girl explained her experience of being deceived by a man who promised to take care of her family and did not. Her younger sibling said:

That because the man told her that she would take care of all of us and he would house.... That she also accepted because she had also got somehow when she does not afford getting money so she decided to get married, so that man can also help her, to give us some money, so that she can also help us.

It was ours and they took it

The household heads in this study who had to flee their land as a result of war were either worried that their land would be taken if they did not get back in time or knew that it already happened.

We have nowhere to go. Even if we are to go there, we have nowhere to start from. People there have grabbed our land also. And if we are to go there, it means we have to buy our land again.

They tease and laugh

Many had difficulties at school trying to fit in with the other children. They were often made fun of for not wearing the right clothes and not eating what others ate. Some would get teased by others about not being wanted by their parents.

Even at school children abuse me anyhow that I put on cheap, cheap clothes, even the knickers I put on [are] 500 knickers [they cost less than a dollar]...I use that money to buy cheap things as if I am not a girl. And now from school people are shaming me because of my living in poverty. And I told them that being poverty doesn't matter. If your father is still there your father I not a goal, he will also will

go away, and you will be bear hand in this hut, and you will come back and cry to me... and then they answer to me that....ahhhh, your father he has died and he has left you because of your laziness that have make you to become poverty. They say those language in Luo, that [she speaks a phrase in Luo-her native language].... and then I reply to them, even though you are ... God in heavens know, and he knows where he is going to put me... even people see me around moving, they think I am coming from a rich family, yet I am not coming from a rich family... my father used to care for us, but now because he is not around, people are just laughing at us.

We were mistreated

In a few child-headed families, when the parents died, the young people ended up living with a relative for a number of years. Many of these young people felt as though they were treated poorly by their relative, often not being given the same conduct as the other children in the household.

Now she is giving us the hard work to do, even this grinding [a staple food], you know grinding sorghum, fetching water from a far distance, doing some bad bad thing even, that is why she was mistreating us like that. Even is she cook food, she can eat with the small ones, and for us we are just staying like that without eating. If we took some small thing, like if we went in the garden and we took a cassava and we eat that one, she scaring us seriously

Theme Four: Coping

In this section I will describe the instances when the young people were moving forward; taking a few steps at a time to handle the situation they were living in. This

includes both the ways the young carers handle their loss, and the ways that they handle the daily stressors in their lives.

Dealing with Their Loss

Being with others

The young people were all able to move on and deal with their struggles as long as they were not left alone to think. Thinking brought a wave of memories and difficult thoughts. As one participant said:

Sometimes, I go to my friends and stay with it, because if I stay me alone, I keep on think about my mother.

It's too difficult to remember

Most young carers believed that remembering made their lives harder, therefore, to make it easier on themselves they would forget. According to one young carer:

[It's] always difficult... sometimes maybe if you forget only, if you forget, you can find as if you are free, but if you start thinking, you find things difficult.

Things that make one remember

The occurrence of certain things throughout the day would cause the young people to remember their hardships and the death of their parents. Many reported noticing how they differed from other people their age. One translator noted that the young person:

He is not associating like going and playing with that peaceful mind... actually it is affecting him. If he is there he does not play with that peaceful mind with other young children out there. He feels like isolated when he is playing out there...

because when he is outside there, he sees how other children they do come, they come when they are... lets say what they put on, their dresses that other children put on, is different than the way he puts on. So when he is playing with other one- those people- he sees himself isolated.

Others felt that the memories came when they were engaging in parental duties that would remind them that they were not a child anymore.

But you know if you are in the house like this, trying to be a parent, trying to do the housework, you can remember and knowing its hurting losing your two parents. So if you are in the house you find difficulties.

Others found they had trouble being alone. Being alone causes them to think, which in turn causes them distress, as one girl described:

It was time me alone, I'm think about my mother and my father. Cause I love him, but now they left me alone, me with my sister, anytime I think about it.

For others, seeing children spending time or talking with their parents caused them to remember and think about their own.

Even if we think about it we cannot choose it because our parents are not there. But if you hear other people think about their encounters you just have to walk away because they can give you many thoughts in your mind, and it can really affect you. Because too much thoughts gives you hardship in life, and make you not settle.

Getting advice to forget

Since remembering and thinking was very difficult for the children to deal with, they would seek out advice from others to forget. The children would receive advice from

friends, neighbours, church members, and their extended family. They were told that thinking would not make their situation better. As one translator pointed out:

They want her not to be in a difficult life...they advise her not to think a lot, 'cause nothing will happen on her.

Others were told to forget and move on with their lives. A translator explained:

They encouraged her to forget about the death of her mother, and then she will continue to take care of the young children.

Another line of advice that was reported among the young carers was to live more like other people:

[We should start] forgetting, not thinking all the time. And trying to also to live like other people, doing what other people are doing, just try.

Consequently, they were reminded that they should be happy that they were still alive; and that they were now the parent and should act like one. As one participant explained:

Because people were telling us that we should not think about those things, cause she has now gone, she is not our parent now...so we should be together, we should not think about her now....

Things that make one forget

Apart from getting advice, the young people would actively seek out ways to not think about their situation or their parents. Some reported sleeping the thoughts away. One girl remarked

Or when I am at sleep- that is when I forget my troubles. But when I wake that is when they all come back to me. And really, that is a terrible time in my life that

really affects me always, everyday. Because if I am at work, I think about my brothers and my sisters, and my life to be... how will that be changed. And that is it.

Others wanted to remain around friends because being alone caused the thoughts to crowd their minds. One translator stated that the young person:

She forget [her troubles] when they are playing together with their friends.

Some of the male heads admitted to self medicating the thoughts away by taking alcohol or drugs.

Sometimes you know these people, young people, they can go outside by drinking, taking alcohol, whatever, it's not good...but sometimes I even used it and everything, because sometimes when my dad died I would say that let me forget some problems I would go into some bars, taking alcohol...

Getting up and doing something productive was the easiest way for the young carers to push the thoughts out of their minds and get through the day.

That doesn't happen, because if you are to lie down who can give you money to buy food, who can prepare for you food and you can never sleep without eating, so I have to work hard everyday, and I work...

Dealing with the Daily Stressors

Happiness

Most of the participants could recall at least one happy thought or memory. Happy times were mostly thought of as when their parents were around although some could pinpoint certain activities or other things they had in their live that they could smile about.

The best part is that maybe I'm happy because we are all together, we just live here in our home, just in life maybe is the thing that we are still studying, three of us.

Not all were able to find that happiness in their present lives. One reported that he was only happy at Christmas when he made more money at the butcher shop where he worked. Another believed that happiness could not be present in the life of an orphan. One young person reported that:

If your parents are gone there's no happy time... but we have stayed long... all the kids....

Let us bear with the condition

Some of the young people reported getting through some tough times by sitting down, composing themselves, and accepting that there was not anything else they could do that day, so they would try again tomorrow.

For him he leaves it as it is.... So if he doesn't have paraffin, he doesn't have money to buy it, he will just accept to go through that darkness, if he doesn't have salt, he will just accept to eat salt-less food, if he doesn't have food then he will sleep hungry, if he doesn't have clothes, he will go naked, until he gets some money and acquire that commodity or that requirement.

One day at a time

Little steps took the pressure away. They did not try to set unattainable goals for themselves, feeling it was easier to take it one day at a time. One male carer said:

Yeah, that's why I have broke every other door- like married...like what I said.

Let me first do the one I can afford now.

Seeing the positives in the situation

Some participants were able to think about what they had instead of what they were missing.

We eat in the late evening then until tomorrow late evening... I think that how, why some of us are losing weight.... But at times I thank God, cause there are some families which can't even afford for getting what to drink, where to stay, but you do appreciate for what god do for us....

Trade-offs

The household heads all noticed that in order to achieve one thing something else had to be done. They needed to dig or work in order to eat. If they ate then they could sleep. One female described the trade-offs in her life:

But if we get, we eat, the thinking we do most is if we eat, so that we can sleep....

However, things were difficult when they had to decide whether they were going to satisfy a need in the present or in the future. Schooling inevitably would help them buy food in the future but in the present if they are going to school then they cannot work to make money to buy food.

And because I am caring for P and I, if I go to school, when I come back nothing we can eat because even at school nobody can work, nobody can bring us anything to eat, nobody can give us money so that we can buy something to cook.

But when I am at home, I struggle and send sometime P to buy sugarcane and K to sell paraffin, when I sometime I go and I work fetch water. Sometime I fetch water then I get money so we eat. But when I was at school, we doesn't eat, and it is also affecting our study.

Trying my level best

The young carers recognized that times were hard but that they were doing all they could do.

For example, if I am at home, then S, when S is not there, I just keep on thinking how we are in this situation, how we are surviving, because at this age other children cannot lead their friend in a good way as I am doing, they would just branch and do whatever they want in this age, but for me I am trying my level best, to handle them to grow up and become a good woman in future.

Turning to God

Putting their faith in God allowed them a sense of being heard. They found a sense of security in knowing that they were not alone and that someone somewhere was looking out for them and would do all they could to protect them.

I just pray to God. If I look behind me and forward, nowhere to go, I just put my heart to God, telling God, praying to God, asking God to help me, today I have nowhere to go, and this children of ours, how am I going to handle them. Today I have nothing. And from there I can see some good Samaritan coming ok R, have this one thing, and share it to your brothers and your sister. And then, if I get

something small then I bring them home and I give them small...small. And then we share in this way.

We can make do

The household heads were very creative in finding ways to acquire those things that they needed most. One young carer explained:

We look for something to do and then we get the money to buy those things.

I am learning to be someone willing to work. The young people quickly learned that they had to be ready at any time to do whatever they could to make money. Even if they were receiving support, it would not cover all of their basic needs. The young carers were self-reliant because everything was so uncertain for them that they learned to depend only on their immediate family. They needed to work to buy their necessities to survive.

What I am learning to be someone willing to work. And to be able to work like in the courses 'cause when you take like in Uganda most of the youth whose of our age, they don't want to mind the kind of jobs around as in this part I work. I work kind of to get something, you know, like that. At least I learn to be fit... to at least the next thing I am facing-what does it require me to do? How best can I improve it so in that I can be able to face any conditions that come my way.

Yeah. At least for that before I had hoped it- where some money couldn't despise anything, provided it could give him something small, yeah.

Let me borrow this, if I get money I will bring you. Many young carers knew of someone in the community that they could turn to when they had absolutely nothing. Sometimes it would be a friend that they would share with. Other times they may know

of a neighbour or a small store that could spare them some food in return for labour or payment the following day.

Sometimes maybe you find that maybe that problem is there... you can go to your friend, maybe because you have nothing to cook or to....then you just go and let me borrow this, just like that, if I get money I will bring you...

Some we eat, others we keep. The participants reported being very thrifty with money when they had it. They would not consume all of it at once. Instead they would use some to eat and others for school fees or other basic necessities.

Of course for us we don't buy expensive food. We can buy posho with g-nuts and we eat. Then we keep that money which has remained because we don't over use it because we have got it that day. And we keep some money for these ones go to school.

Sometimes they needed to save a bit of money so that they could turn around and use it to make more money. In the following example, the young people are talking about buying sugarcane to sell it and make a profit. However, they expressed that they always needed to make sure they kept enough money to continue to buy sugarcane for the purpose of selling it each and every day.

Yeah. They go back. They try. If it get, we pay the other money, then the remaining money we eat. So but make sure that even if we don't have what to eat, we make sure that we keep over \$1000 again to go back and buy...cause if we finish all the money...it will be bad for us cause we have eaten all of it.

The best thing is our parents left us with a house. Some child-headed households were left with a house on land when their parents died and as long as it was

not falling apart they had a shelter that they did not have to worry about paying on a monthly basis. One boy in Jinja district said:

The best thing is that our parents left us with a house, we are not renting...

When they had multiple rooms in their house, or land that they could build additional shelter on, some young people rented the rooms out to other families to make some money.

But for us here...in this room, we are eight but there are six that can help us...cause I can say three rooms, this one here, I got one room, the one who stays inside there, is the constructor build eh, .. then we decided if a month elapses...instead of giving us cash, so what we do is maybe the veranda is spoiled, he buys us a stack of cement, then this neighbour we count using the month without using any cash. Like there is some construction which is taking just up there...so it is somehow slow, but we believe at least we can...

We use what's available in our community. Some of the young carers found cheaper schools and free hospitals in their community that they could use. They would also gather materials from the bush to make their house, and would specifically move to a community where services were provided to help.

So, we can go and there's some schools that if you say that you'll pay some day, they can – that is the cheaper school in Uganda. And we are going there...you know these ones- cheaper compared to the boarding school... and that school is a catholic school, at least can support orphans, so we can tell them that we are orphans so they don't so much chase us from school sometimes.

We work where we can to survive. Every young carer had some income generating activity that they did to keep them going on a daily basis. They did anything from laying bricks, to fetching water, to caring for other children, to digging in the garden to working at a butcher, to making chapattis for people at night, to fixing locks and setting keys. They all knew that they needed money in order to survive. While I was talking with one boy in a rural village in Rakai, his translator explained:

That he goes for digging in the morning... that if he doesn't dig in their garden, he goes to provide labour at that other lady's household where he can get food... then he comes back with the food and pail... then he cooks... then the rest of the siblings go for water, and firewood... that in the evenings, he goes back, after having lunch, he goes back and does some petty work where he gets some money to cater for the family...that when he goes the siblings he leaves at home, prepare food for supper, so when he comes back he bathes then they take supper and go to bed...

Theme Five: Acceptance

I look at this as the point in the cycle when the young carers were standing up nice and strong with their hands on their hips saying, "yeah I can do it". One female head responded:

I am taking care of my children, which are left. But now I am lonely. I am a father, I am a mother.

Although they all described their uncertainties, knowing it would be difficult, they all knew in their hearts that caring was something they had to do:

Like for us we have to do all things for ourselves. Like to be a child parent is not simple. And if you are not determined in your life you better give up.

In this section I will describe the feelings the young carers expressed as they came to accept their new role as parent.

At First I Didn't Believe It

Many household heads reported that even though they were warned in some way by their parents, that they did not believe their fate until they were actually left alone.

Ok, at the time my dad died I was the first born in the family, he usually told me I was to care for your young brothers and girl [sisters], okay he say it like a lie or a joke, by the time he died, I was left the one to care for them.

Not My Choice

Many young carers were very young when their parents died. Therefore, although they took on the responsibility, it was not a choice for them. They believed that there was no other option and the choice was made for them already. When talking to a young female household head, her translator said:

That she could fight because she could not want people to tell her that you go take care of all your young ones, because she felt bad, instead of playing, they could tell her, you go and take care of your young.

Being Prepared

In Uganda it is commonplace for children to be taught at a young age how to take care of a household. If the parents are out working, the children would make the food and fetch the water and sweep their compound. This was especially evident when a family was surviving on very little. All of the members would come together and do their part to

help out. So even though the young people may not have been mentally prepared to be the primary caregiver, some had the skill set to take over the household.

[laugh])... you know in our land... in our culture if you are a child, and if you know that you really have problems, you must know everything. You don't say this one I cannot manage, and this one I can manage. All of you must work equally.

Learning to do It

Most household heads reported that they learned how to take care of their siblings from their parents.

Because our mother was bright enough to teach us all those things when we were young. Being a first born in the family.... They are focused on you, your mother will want to teach you everything, so that someday you will be able to teach other children.

However, some were so young that they were not able to learn all they could before their parents died. These household heads felt as though they learned how to care through their experience over the years. They believed that it was really difficult in the beginning but that it got easier over time as they grew and matured. The younger brother of a female head told me:

That it's not the same because when she was still young she was not taking care of us very well because she was also somehow very young when she does not know anything. But now she knows things so she should take care of us as a person who is big.

Others believed that they just took things as they came and dealt with one situation at a time, not learning from anything or anyone in particular.

I can't tell you how I learned cause I don't know... it's just, we are just finding myself doing some of the things in that way, cause at least I get time to think of... the challenge comes and then you have to provide its answer, that's how I get to learn...

Being Mature Enough

The household heads knew that the state of maturity meant knowledge, experience, and being able to handle things like a big person would.

And by then we were young and she couldn't say that I don't have sugar, she couldn't say there was no salt... but now, since we have matured, we had to forgo sugar because it is so expensive.

Staying and Working Together

Many of the household heads had such difficulties with being alone that they would do anything to remain with their siblings. There was nothing that could tear them apart.

If even at my level, even if I get something I can continue helping them like that until they grow in a good way, if they get job they can stay like that even...they would continue stay like that... Even if I got my family, I'm going to continue staying with them like that... nothing is going to separate us.

Some believed that things were not going to be better no matter where they were. Therefore, separating and moving around would not help them at all. They chose to stay together. One family felt:

For us we know our problem now. Even if we go somewhere else we will not get anything. So we try to stay together.

Some families had siblings leave the household for different reasons including to start their own family, to go to school, or to work. In these families, the second in line would take over the responsibility. However, there were a few instances where some of the younger siblings were living with a family member because the household head admitted they could not possibly take care of so many children on their own.

Now when the mom passed away, what happened is he had to send some- I mean the other brothers at home, because the mom is not there now and what he had to do to send other people home and remain with these one he can afford, with what actually he is doing.

Giving Up Myself for My Young

Many of the young people had to give up important things in their lives in order to take on the responsibility of parenting. Some stopped schooling in order to work so that the younger ones could attend school. Many gave up the idea of getting married and starting a family of their own. Others gave up spending time with young people their age – doing sports or other activities, or would forgo eating so that their siblings could eat.

You know, it pains me. But I can't. I said, no. Let me go and I cater for my young brothers and sisters because it's useless to get school when they are dying because of hunger. And I said let me go and cater for them.

People See Me Like a Parent

Parents are the ones to provide for their children. The household heads were treated like a parent and were often given the respect that a parent would receive from their peers and siblings. A younger brother explained this about his older brother:

I see him as a parent in that however much the problem may be, he may try all his level best to see that we people, that we don't suffer. Instead of us suffering he is the one to suffer for us, 'cause he is now like a parent.

But sometimes the household head played a dual role- both an older sibling and a parent. They allowed their child-like side to emerge every once in a while. A younger brother described the situation with his older brother:

He's the same of....something like stubborn....small stubborn....I was punching him like this and I get.... [he shows me his torn shirt].... [laughs].... 'cause he was disturbing me in the morning....I was having my shoes today... and he took one from my leg... I punch him like this then my nail [he shows me how it went through the shirt], and I teared it....so close.... [they start laughing and looking at each other].... He's joking me....he's a brother because we were born together and he's a parent because he pays for the house and sleeping, he pays for the school fees, and then he feeds me... yes....

Making Choices

It was inevitable that in acting as the parent, the household heads were forced to make difficult choices on a daily basis. One female head said:

That is what I can choose from there.... I can see that.... [sigh]..... it is very hard....

The young carers all explained their thoughts on the choices they were forced to make. Below I have described the three categories their thoughts fell into: don't let change- change you, what's most important, and my time.

Don't let change-change you

They know what they want in their life and they chose to not give in to external pressures or desires. They know that rushing into something might not be the best option and that if they continue to make small steps towards their goal they will achieve it in time.

I see that, you know, if you are a wise person, you have not make change-change you. You have to have a solid heart to achieve what you want before to respond to changes....you know those changes are minor desires of the world. But we are first to make our situation better that is when we incorporate with others. So I don't think that someday we shall meet our family earlier before.... You know if you want your family you should have set other things that will support you... that will support your family. Like if I am not educated there is no need to have a family that would suffer someday at least. I first have to be educated. I have something to do that someday I might also help with my family...yeah...

What's most important

It is a constant struggle for those young people having to choose what the most important thing is to put their efforts on each day. All the households agreed that education and food topped their lists. Shelter, clothes, and other basic necessities followed after.

The most important thing if I get money...yeah the most is to get school fees and food because they are the most important... maybe this house in time if God will like I will make it, but the most important... because school fees and eating... like shoes and clothes because they want to wear clothes, they want to wear shoes, ok and chose those stuffs, that's the most way.

However, sometimes there was only enough money to choose either school or food. Each household head made a different decision in regards to that depending on their situation. Some young carers would choose to pay their school fees instead of eat. The following is from an interview I had with a 16 year old girl caring for her three siblings. All of them were presently in school.

My basic needs are food and education... [if you had a choice to have either food or education?].... I will choose education... [why?].... because education is good...even it will help me in future... [even if you haven't eaten?].... I would struggle.

Other child-headed families put food first and then spend the rest on education. The following is part of an interview with a 17 year old female who was not in school.

Food is first and then...extra money we keep for them to go to school...[and then next?].... hmm ... Sister, the money we get is very little because we cannot manage to get money over 3000 [Ugandan shillings –approximately \$1.50 Canadian]. I just look at it. We just get about 1500 [less than 1 dollar]. That's all.

My time

Some young carers talked about using their free time to spend time with their friends, participate in sports, or play music. Others considered attending mass and having time to study as their free time. Nonetheless it was time that they allowed themselves to do something they wanted to do.

Especially me, everyday I joined the club... that is why I talked about it with you.

I joined club, after working preparing all these children, I go and play, that is my leisure time at least I become happy.

However, not all young carers reported that they had free time. One young person in particular simply said, “no, I don’t get time”.

Theme Six: Hope

In this section, I will highlight examples from the interviews in which the participants expressed their hopes for the future. Regardless of the difficulties they were facing, they all saw a positive light which they were striving towards. This kept them focussed and determined to move on. One young carer explained:

This position [being the parent], I like it ‘cause of the challenges I am facing. I believe in the future, I will be able to manage many of my roles according to what I’ve faced.

Education is the key of everything

All the participants believed that education was the only way that they could attain a decent future. One boy felt that it would bring about a change in his life:

I think if I’m at school I can start again, my life would change in the future... I think after education I think life can change.

For others, education acted as their parent. It was sometimes the only interaction these young people had with an adult. It was the only thing that was allowing them to learn about how to live their life.

The reason why I need to go to school [is] because only education will be my father and my mother. These are the only things that can make my life better for my brother and sister....education is the only parent of us...

An easy life

With education, an easy life was thought to emerge. They felt that upon passing their courses they will have a better chance at a good job, in turn making them the money to provide for their brothers and sisters. An easy life is one in which they have everything they need, and they are not plagued by thoughts of better times before.

I think that for now to make it easy, it is when you have something to do, which can make you get money, which can make your life easy, but now if you are like that, life will not be simple. At least you have something to do, get money, can make your life easy.

What I want

The young carers wanted a means to a better future. This often meant that education was first, followed by a good job that provided them with enough money to support their siblings. When asked what he wanted, one boy replied:

My goals...I want to finish up my study, get a good job so that I can take care of my brothers, maybe my brothers and sisters.... so that we can have a good life maybe.

However, some participants simply wanted help with a skill or a means of income generation like a bike, or start-up materials so that they could sustain themselves. This was often the case with household heads who had never been to school or who had been away from school for many years, as one translator stated:

Yes he is hoping at least to get something at least something to do, to make them feed on. But actually he have no clue because he has even not studied....

Getting somewhere good

The ideal goal for their future was to attain something good. This varied for every one of the households but in essence it meant that they would not be struggling day to day, that they would remain together, that they would have enough, that they would be mature (having knowledge or skills), and that they would not be plagued by their deep thoughts. One young person said:

A better life look like this: person who don't have certain things [to think about], don't think deep things, they are very happy all the time.

A young male carer also explained:

A good life may be to be living ok, like living day to day when you are having something to eat, ensuring everyone is happy at least at home, everything is ok, there is food, there is water, electricity....

Giving hope to others

With advice there was a sense of hope. Household heads both sought advice from others, and gave it willingly to their siblings and friends. It was a common practice that reportedly helped them through some tough times.

Being strong. Some would advise others to be tough and to be ready to take on anything as it comes their way, as one young carer said:

I would just advise them to be strong in whatever situation they experience, 'cause we are living in a changing world and no one can fight change.

Cooperation and togetherness. Most household heads believed that the only way they were surviving was because they were sticking together. Therefore, they would continue to remind their siblings this and would advise this of others who were in the same situation as they are:

Then I told them if they will struggle, and we work hand in hand, in the field, everywhere, we should be cooperative among us. Then we will make something in future.

Don't covet others. The household heads recognized that it was harder to deal if they were constantly judging themselves against others, wanting what material possessions they might have. They advised that people should know their place in this world and should not put so much emphasis on achieving to the standard of others.

You don't admire your friend's property, of which you know you cannot afford. If you compare yourself with your friend, as this one he or she is having this one, or you- for me I don't have – I should struggle and get it. But you know your background, and I told them that you know where you come from.

Encouragement to continue. Household heads reported advising others to not give up, but rather to keep going with what they are doing because things will get better. One young carer talked of her advice to her siblings:

For me I want to encourage them to keep up this period, they should stay in the

future alone [because] there is no permanent condition, their condition will change with time.

Pray to God. Knowing that someone would be there to help them through the tough times and to get somewhere in their lives eased the struggle. Many turned to God because they felt welcome into the community or because they were receiving support, and would advise their siblings to do the same:

Maybe [I would tell them] to just believe in God, because with God everything is possible...

Put effort in education. As I stated previously, the child-heads pushed for education thinking that it was the only way to a better future, and they felt it was important for their younger siblings and other young people in their situation to do the same. At a camp outside Gulu town, a translator told me that the young woman she was talking to said:

She advise that person that she put more effort on education, like her, to be a teacher like she want to be a teacher...

The young carers believed that people should stay in school if they had any opportunity to do so, as one girl explained:

Yeah maybe for me I would like to advise them maybe to stay in school if they still had support from anywhere, they stay in school – study- they never know where in time they will be in their situations...

Work hard. Their work ethic was simple- do whatever you can to survive. They believed that there was no point thinking that something could not be done. They did not have much choice- they had to work in order to survive. In each household the young

people would all do their share to help out. When asked what one young carer would like to tell other young carers like herself, she replied:

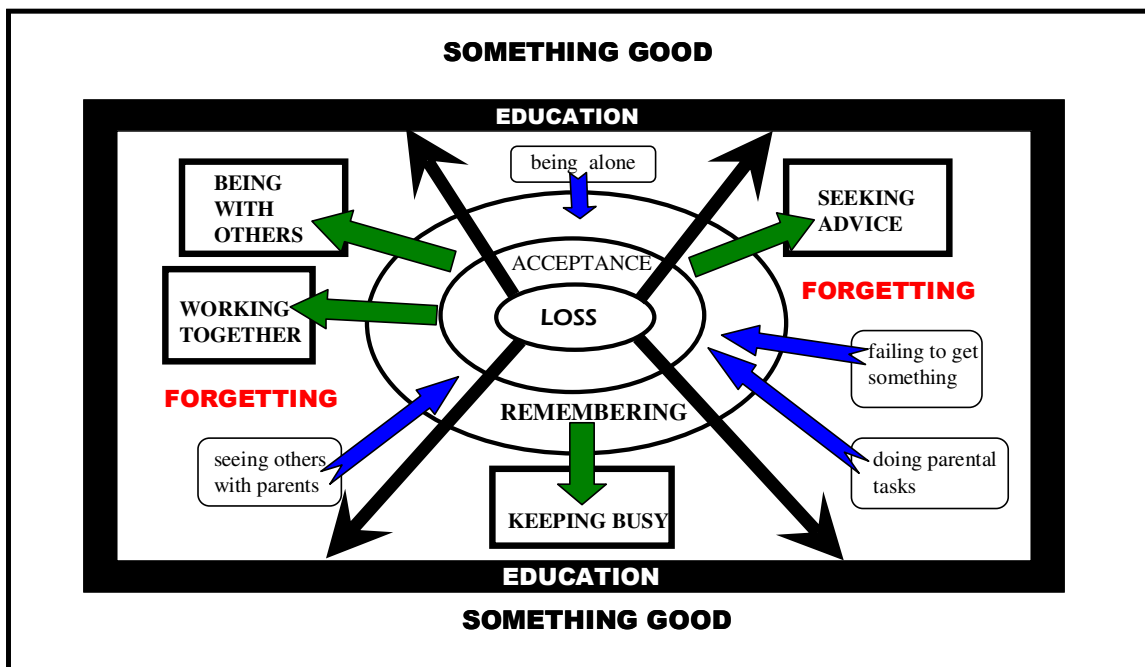
I'd tell them I am in the same problem... the advice I'd give to them- to get, even a little job to do.... any job...don't fear any job.

CHAPTER VI

Discussion

Based on the experiences shared by the young carers who participated in the study, I was able to create a conceptualization of the affect that the caring role has had on their lives. These young people have all experienced the loss of their caretakers, thus taking on the role of being a caretaker themselves. Upon accepting this role, their daily lives are filled with numerous stressors which keep them in a cycle- trying to forget but constantly being reminded by certain things. In turn they push for education, believing that only with education will their lives change. Education will pull them out of the cycle because they will not have to deal with those daily stressors anymore, in turn allowing their life to be good. The model that had been created to represent this idea is depicted below.

Figure 1 Getting Out of the Coping/Grief Cycle



Over the next few paragraphs I will explain the model.

Child-headed households have all experienced loss. Many have experienced not only the loss of both of their parents but also the loss of a step-mother, a grandmother, an auntie, an uncle, or a neighbour who may have stepped in to help them right after the loss of their parents. The multiple losses occurred for many different reasons. AIDS is rampant throughout the country and continues to affect many families. Automobile accidents and sickness due to many communicable diseases, causing death, is also common. Also, some young carers who are from, or continue to live in Northern Uganda have lost their parents as a result of war. Also evident are multiple other losses apart from death these children are faced with. They may have lost their chance at an education, the loss of their childhood, or they may feel neglected by friends or extended family members. Whatever the case, loss holds the core of the model because it is the root tying all these young people together.

After the loss of his/her parents, when the eldest child is left alone with his/her siblings, he/she goes through a process of appraisal, evaluating his/her stake in the loss, what can be done about it, and looking at his/her options. Every young carer made the decision (whether they feel like they had a choice or not) to care. They took control and began adapting to the role of being the mother and father to their siblings. They accepted the responsibility. This was the first step. Lazarus (1993) defines this step as a form of emotion –focused coping. In some of the literature on child carers in Africa, this act of taking on the caring role is considered as a new coping mechanism to dealing with the problem of being an orphan (Kuhanen, Shemeikka, Notkola, & Nghixulifwa, 2008; Foster, 2000; Foster et al., 1997).

The young people are responding to their loss through a grief reaction. Grief is “an experience that is ongoing, that changes in nature over time, but that involves a continuing relationship with the deceased (pg.1)” (Moules, Simonson, Prins, Angus, Bell, 2004). These young people are continuing their relationship with their parents. They cry, they have nightmares, they feel sadness, deep sorrow, and worry, they express uncertainty, loneliness, and fear, and they question “why”, knowing that their life has changed and “there’s nothing I can do”.

Lazarus (2006) defined coping as an effort to manage adaptational demands and the emotions they generate. What I was seeing with these young carers is that when their methods of coping with the stressors affecting their daily lives failed, they were thrust back into this grief response. The young people would engage in behavioural and environmental adaptations in order to forget. They would seek the comfort of a close friend, they would turn to someone for advice, they would busy themselves with housework or paid work, or they would participate in sports or activities such as singing, dancing, or playing music. However, when times get tough, when they have absolutely no food, when they cannot find work to make money, when they are left all alone, or when they see other children with their parents, when they cannot manage to consistently achieve these efforts, they are flushed with emotions full of grief.

Both forms of coping, defined by Lazarus (1993) as task-focused and emotions-focused, play a part in the lives of these child-headed households. The inside of the rectangle shows the young carer’s engagement with forms of emotion-focused coping. They are self-controlling (they seek social support from neighbours friends and relatives), and they have escape-avoidance reactions when they are around peers that are talking

about their parents or when they are around children with their parents. The outside two rectangles, showing the push that these carers have for education to bring them a good life, represent their coping through problem-focused means. The findings of this study support the findings of Lazarus (1993) that these two methods of coping go hand in hand.

Folkman et al. (1986) found that those stressors that are felt to be changeable are coped with in a different way than those which had to be accepted. In their study, participants coped with changeable situations by maintaining focus on the situation at hand: they confronted, did planful problem-solving, accepted responsibility, and focussed on the positives of the situation. They found that accepting responsibility through behavioural self-blame may have the ability to promote problem-focused efforts. Similarly, in the present study, many young carers approached their family life with the idea that they were the ones who were mature enough, that they were in charge and they were the only ones able to and meant to do something about their situation. Therefore they pushed for education if not for themselves then for their younger siblings, because they felt as though they could change the situation for the better. They often believed that they were the only hope, knowing that without them, the younger ones would not survive.

Alternatively, in the study by Folkman et al. (1986) when the situation was viewed as having to be accepted, participants tried to not focus on what was causing them distress, through distancing and escape- avoidance reactions. Along the same lines, when the young carers were confronted with a situation which caused them to remember, they would try to remove themselves from the situation in an attempt to forget.

However, Ben-Zur (2005) suggested that people use either problem or emotion focused coping. He looked at the differences in distress levels caused by problem and

emotion focussed coping, and found that problem-focused coping strategies are slightly effective in decreasing distress, while emotion-focused efforts increase it. Therefore, those who use problem focused coping methods fare better under stress than those who use the other. Likewise, this study suggests that maybe young carers have a strong ability to handle the immense stress in their situation because they are found to use both methods interchangeably (similar to Folkman et al., 1986).

The model I propose depicts this cycle of grief and coping the child-headed households in Uganda are experiencing. They are living within an environment in which they continue to pathologize their situation. They refer to the loss of their parents as a problem that must be overcome, and they actively seek a means in order to overcome it. Temporarily, they forget to move on but they ultimately try to solve their problem by looking to the future. They do not want to remember because this brings unwanted distress. Similar to my findings that these young people experienced higher levels of distress upon remembering, Neimeyer, Baldwin, and Gillies (2006) found that those who have experienced a loss are troubled with greater distress when they have an ongoing bond with the deceased.

There is a strong belief among these child-headed households that if they make something of their lives, if they have a good life, then they will not be missing their parents anymore. They make sense of it by thinking that parents are there to provide for their kids. As new parents they struggle to provide for the younger ones which makes them think about their parents and miss what they used to have. But, if they are able to get an education and be able to provide their siblings and themselves with a good life,

then they will not miss their parents anymore and they will have put an end to their feelings of grief.

Over the past 10 years, researchers have begun to challenge many studies that have emerged contradicting traditional beliefs that grief is something that must be resolved, or that it is something that is pathological (Moules, Simonson, Prins, Angus, Bell, 2004). However, my findings show that among this population of young people, grief is being pathologized. The young carers are told it is something they have to get over so they begin to internalize their thoughts and feelings. They think that they need to rid themselves of this problem and the only way to do it is to seek out those ways that allow them to forget. It is this active seeking of ways to forget which shows their beliefs that grief is a pathology and it is something they have to rid their lives of. The idea proposed by Moules et al. (2004) that grief resolution is traditionally looked at as expected, normal and possible, although it should rather be seen as a continuous lifelong component, speaks to the potential for added distress that their attempt to try to forget has had on their lives.

Most of the young carers who seek advice look for it within their community from people that may not be taking care of siblings like them but who are struggling to get by in the same fashion. Buckley-Zistel (2006) refer to this effect as "chosen amnesia". They reference this effect to the people of Rwanda in how they are dealing with the genocide. However, it is typical that in the communities in Uganda that the child-headed households are living, many people are struggling. The communities surrounding these young carers are all living in material poverty, working day to day to try to make ends meet, while at the same time facing issues of AIDS, war, and other sicknesses plaguing

their families. They are all trying to forget about the past or not dwell on their situation by ignoring those feelings of grief. The young carers are all told to put what has happened behind them in order to look forward to the future. This is how these young people have been coping with the grief reactions that they are experiencing. Everyone around them tells them to forget. They forget about their parents, forget about their hardships, and they do what they need in order to survive. However, we don't know if they are really forgetting or just trying very hard to forget. The dynamics operating here would be worth further exploration in future research.

CHAPTER VII

Implications for Social Work Practice

The research presented has many implications for social work practice with child-headed families. As the research suggests, support should be strengths-focused, family-centered, community-based, trustworthy and dependable. Also, service providers should recognize the cycle of grief these children are experiencing as well as the trade-offs and choices that the children are forced to make daily.

I believe any approach to assisting these young carers must be family-centered as we are dealing here with families. This is contrary to the belief of Plan (2005) that support should be child-centered. The young people have made a life-long commitment to themselves to care for their younger siblings. They have shown that they put the needs of their young ahead of their own, and their future plans and goals include them all as a united whole. Therefore, any type of support has to include the entire family, not just certain members (as was reported to be the case with services the children know of or are assisted by). Similarly, in a study by UNICEF (2003), it was found that separating siblings who have become orphaned significantly increases their levels of trauma.

The household heads reported many issues with access to services. Some of the young people reported not knowing of services in their community. If they did access a service, they either didn't trust them or felt that they could not depend on them long-term. Many services were also said to make false promises or to not speak with the young carers because they needed "someone big" to sign them up. Similar results were found in a previous study in Uganda where only 5% of orphans were found to be reached by

NGO's, government programs, and other donors, while CBO's reached a mere 0.4% of all orphans (Deininger, Garcia, & Siibbarao, 2003).

Since many of the young carers have experienced such limitations or barriers to receiving supportive services, the young people tend to turn to people in the community for support more than looking to formal organizations. They would talk to a neighbour, relative or a friend when they were feeling immense grief or were struggling to get by. These young people would also borrow or trade with individuals in their community they knew would support them. They expressed that they would rather discuss their feelings with people whom they knew were in a similar situation rather than someone on the outside. Therefore, support should be aimed at strengthening small scale supports in the community – bringing young people together in group situations to have a support network of peers in a similar situation, helping them to find a neighbour or a friend in the community, or helping them to secure a means of income generation within their community. This finding parallels that of UNICEF (2003) in which communities were found to be at the forefront of caring, both financially and emotionally, for all vulnerable households in Africa. Community initiatives such as identifying and visiting children in the community who were without parents was also found to be helpful in addressing the basic needs of the population (Drew, Makufa, & Foster, 1998; Foster et al., 1997).

Another important aspect that was brought to light in the interviews was that the young carers were not only pushing to attain “something good”, but they also wanted to “be good”. They internalized their struggle. To be good was to do something good with their lives, like finding a good job and making money in the future. Often, those who were in school and learning were deemed good people because they would be able to

achieve something better. However, the strengths that they possessed were often not acknowledged by those around them. One male carer said:

What I want to see happening is like everyone has to be kind of involved at least somewhere...with the people around them at least maybe, also be able to use some of their talents 'cause at least you know in talent someone is able to achieve. It's like a stepping stone, one's talent I mean, that's why most of the students with their parents fail to achieve because they don't see their talent... forgetting ...

Some young people knew they had something they were good at but when it is not acknowledged by others then it often can go unnoticed. What they were looking for was to "be good" in the eyes of others. Maybe this influenced them to the extent that they were not "good" because they were not like everyone else and they desperately wanted to be like everyone else. Is it possible that their desire to fit in meant denying their personal strengths? We have to recognize that for each step backwards that these young people are taking, that they are taking many steps forward. Young carers have many strengths which are left unnoticed. Yet these strengths are what can be built upon as a guideline for support.

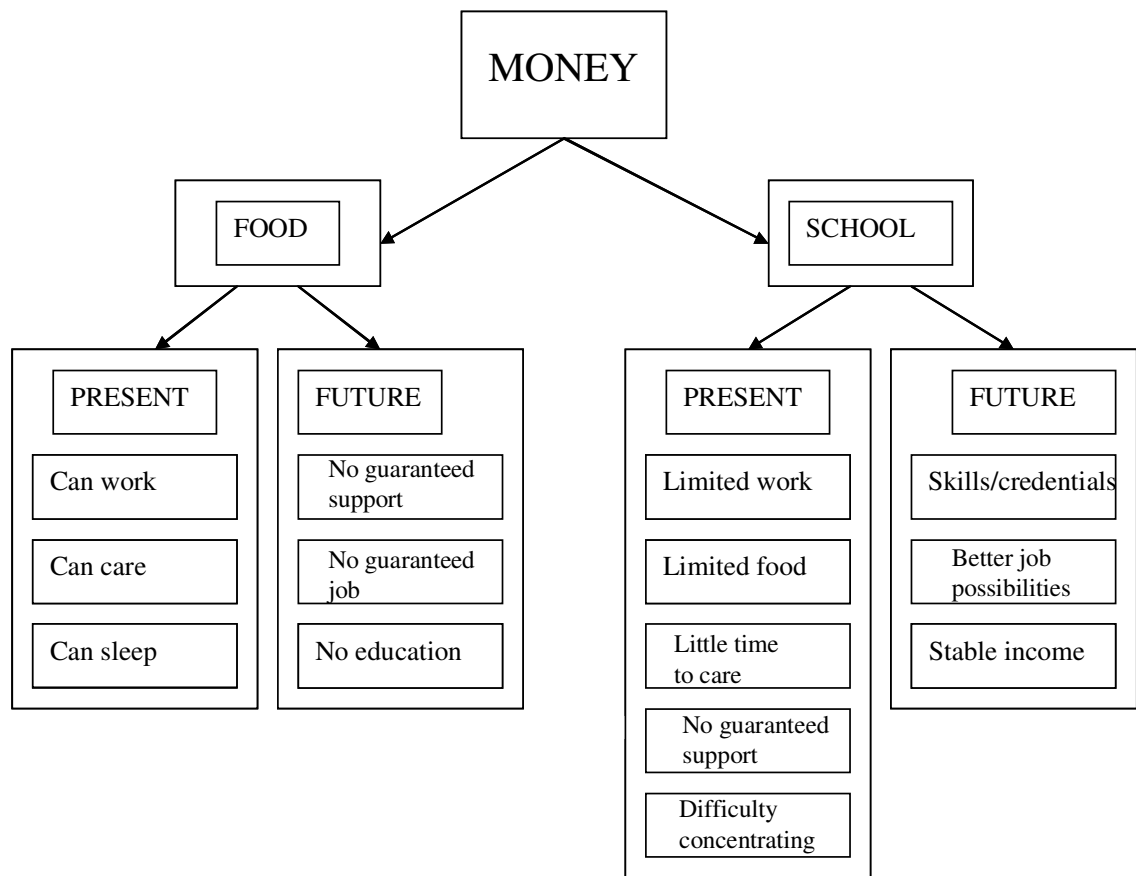
Many studies have discussed the numerous psychosocial issues that have been found to plague orphans (UNICEF, 2003; Atwine, Cantor-Graae, & Bajunirwe, 2005; Becker, 2007; Foster, 2002). This study showed that the young carers were all experiencing grief after their losses. Many were also experiencing suicidal ideas and were vulnerable to unwanted sexual encounters. They were all experiencing many hardships from taking on the responsibility of their siblings. I believe that these are crucial issues that should definitely be addressed as supports are created. However, the problem is that

everyone is focussed on thinking “these poor children” instead of thinking “these amazing children”. No one is looking at their unique and amazing talents and abilities. They are hard-working, hopeful, determined, committed, loving, caring, and intelligent people. Organizations and support networks should be acknowledging the strengths of these young people and using them as a basis for support. In a report by Plan International (2005) it was noted that child-headed households show a capability and resourcefulness in the ways they handle their situation. Although their study focussed solely on the AIDS orphans in Rakai district, Plan (2005) suggested that programs should be created to expand on the capabilities of this population, rather than provide bandaid approaches.

Muller & Abbas (1990) found that orphans have less access to an education as a result of a lack of money to pay for school fees. In turn, organizations such as the Federation for Education and Development (in Jinja district) and Meeting Point (in Kampala) have focussed their efforts on paying the school fees of young people who are orphaned. However, as the model below depicts, and the present findings showed, this results in young carers having to face numerous trade-offs and difficult choices in order to get that education. The research showed that the participants believed that when they attend school, they have better opportunities available to them in the future, but they experience a much more difficult present. Alternatively, if they put their efforts into working to survive in the present, they will continue to struggle, living day to day in their future. The young carers feel that education is the key to their future, and most will do anything they can in order to achieve that education, even if it means missing out on food. Therefore, services that only pay for school fees create many hardships for the

young people to make ends meet on a daily basis. This supports findings that programs for child-headed households should not create unnecessary burdens for the child head (Plan, 2005). Similarly, Kuhanen, Shemeikka, Notkola, and Nghixulifwa (2008), suggest that in order to meet the educational needs of this population, new educational approaches should be developed which foster both formal learning and the development of the practical skills necessary to survive.

Figure 2 The Trade-Offs Faced with Choices Made



Additionally, findings of the research uncovered that the child heads experienced more distress upon remembering, and that may be due to them feeling that their situation was pathological and needed to be fixed (Moules et al., 2004). However, if ideas of Neimeyer, Baldwin, and Gillies (2006) are validated in which children are supported to make sense of their loss (and in turn their new situation) in ways that are meaningful to them, then they may not experience such complicated grief. Similarly, Foster (2002) suggests that programs must acknowledge the emotional needs of the young carers, rather than solely focusing on material support, in order to prevent continued distress in the future. Therefore an entire community change will need to take place to support a plan for child-headed households in Uganda. Since children turn more to members of their community for support, these members have to also believe that it is okay to talk about their parents and try to figure it out, and supporting them to do that may be the key to them coming to terms with their grief.

Based on the reports of the young people, some services are present or available in their community but there are barriers to access. Social workers could be crucial to help mobilize services in an attempt to connect these young people with the supports. However, there are limitations to the services as they do not have the resources to help every young person who could benefit from them. They are also limited in what they provide to these young people. Since these young people are different than other children who are orphaned in Uganda, supports should be created specific to supporting these children in their situation. Sustainable supports focussing on the entire child (physically, mentally, emotionally, spiritually), and based in the community are the most needed for this population. However, it is crucial to listen to the young people and to base the

supports at the point a young carer (and his/her family) is at in their journey. We have seen that each young carer has his/her own unique abilities thus supports should be created specific to each family using these general guidelines outlined by the young carers.

Basic education is supposed to be free for all children in Uganda; however, many children are prevented from attending school because of being unable to pay the extra fees. This should be a priority for local government councils as they are responsible to safeguard and promote the welfare of the children in their district (The Children Act, 1997). However, contrary to suggestions by The African Charter on the Rights and Welfare of the Child (1999), these young carers did not want to be placed in alternative care arrangements such as foster care or institutions. Rather, they wanted to be supported as carer-givers in their community- a policy set out by the Uganda Children's Statute (Organization of African Unity, 1999). This Children's Statute also stresses that young people should be fully involved in solutions to issues affecting their lives, which is key as this new generation of child parents emerges. The problem is that although this collective legislation to support young people in Uganda is instituted, it is not evident in the lives of this population. As an increasing number of child-headed households are arising in the country, resources to support these young people should be a priority.

CHAPTER VIII

Directions and Limitations of Research

Directions for Future Research

The findings of the present study provide a basis for the emergence of further research to be done with this population of young people. While most of the research on these young carers to date has focussed on statistical means to gather information, this study demonstrates that young carers who are given a voice have a lot of insight to inform us of their situation.

This study only focussed on the child carers who were without adults in the home, but additional information could be found from those children who care for their siblings and a sick or elderly carer for an extended amount of time. Similarly, the validity of the model depicting the cycle of experiences the young people face could be tested on other child carers in different areas in Uganda or child carers in different countries in Africa.

Long-term, longitudinal studies into this population would best aid us in determining methods for best practice. Studies that aim to look closer into what effects that forgetting has on the future of these kids will help us to figure out how to best support them emotionally. Studies also focussing on trying different methods of psychosocial support, like group work, in order to get feedback from the participants could prove to be helpful.

Also, whether an education will provide a significant change in the lives of these children is left unexplored. Studies should focus on the level of education needed to provide a life change, and whether the focus on at least attaining a primary education proves worthwhile. Also, a deeper look into the level of distress caused to young carers

while they are educating, and looking at whether they felt like it was worth it in the end could be helpful.

Additionally, formal supports were found to be inaccessible and inadequate in providing the basic needs for this population of young people. Further research is needed to look at the reasons for the numerous barriers that are evident in service delivery for this population, so that once adequate services are created to meet their needs, they will be able to reach the young people who need them most.

Limitations of Research

The focus of the interviews was pre-determined, and this, along with the pre-set questions, could have limited the findings. However, the questions were used only as a prompt to assist the young carers in the narration of their story. The participants were encouraged to discuss whatever they felt a desire to.

Further, the child-headed households who participated in the study all had some connection with a service provider or a community leader in their area. There are many young carers who are isolated and not known to services and these young people may have different experiences to report. As well, some interviews were conducted via a translator. This limited my ability to guarantee that the words of the young person were translated verbatim and that nothing was lost in the course of the translation.

Although a preliminary analysis was done following each interview to refocus and add or delete questions, the bulk of the analysis was done here in Canada. This occurred because I had a lack of resources and time while in Uganda. As well, I was limited to one meeting with each child-headed household who participated. These aspects

both prevented me from checking my analysis and findings with the participants, and barred me from asking further questions for expansion or clarification on arising themes.

The results of the research highlight only those experiences of the 34 participants, and although I have been able to make a few recommendations consistent with other larger studies, they cannot be thought of as a representation of all child-headed households. Further research is required to look at the emergent patterns more extensively

The findings and their application to support are limited to those service providers and professionals who can be contacted in Uganda. Many individuals in smaller community based organizations with a lack of resources, who may find the results useful, may not ever get to read them. However, I do plan to do all I can to get the information out to those who could use it.

I originally chose to inform the research by a grounded theory methodology because I felt that it would allow me to dig deeper into the lives of these young carers in order to really make meaning of their experiences and co-construct knowledge with them. In looking back at this decision, it is possible that using a different methodology, such as ethnography, may have been more conducive because I was unable to carry out all aspects of grounded theory as they were set out to be used. Nonetheless, Corbin and Strauss (2008) believed that researchers could be creative in their use of grounded theory strategies and how they carry out procedures, but they must use all of the major procedures that were a part of grounded theory to maintain credibility. They felt the core components of grounded theory were: constant comparison, use of concepts, theoretical sampling, theoretical saturation, the construction of a well-delineated theory, concurrent

data collection and analysis, beginning analysis with the first interview, and memo writing. They also stated that there is an ideal way and a practical way of doing research and that sometimes the researcher has to settle for the latter. Consequently, I believe that I was able to use the above mentioned guidelines throughout the research study although I did have to use them in ways that were practical to the means and confines of this study. Therefore I believe that informing this research in a grounded theory methodology was a good choice because it allowed me to create a practical model that can be used in the future as more and more information is accumulated on these young carers. This would not have been the case if I would have used a different methodology. However, it is something that should be considered as future studies are conducted.

CHAPTER IX

Conclusion

This paper highlights findings from interviews conducted with 34 child-headed households throughout four districts in Uganda. Six crucial themes emerged from the data, which enabled the creation of a model explaining the affect experienced by these child-heads. The household heads identified their experiences of loss, reactions along with the reactions of the community, the vulnerabilities they face, coping with loss and daily stressors, acceptance of the role as a parent, and their hopes for the future. They also identified the trade-offs associated with the decisions they make on a daily basis.

The core objective of the research conducted was to understand the essence of their experiences with being a carer and to develop a conceptualization that explains that experience. The aim is to recognize that these young people play a vital role in the community and, as such, should be supported in planning and carrying out efforts to lessen the affect that caring for other children may have on themselves. Although I cannot guarantee that the young people interviewed will receive support any time soon, I am hoping that the results of my research will be helpful in the development of the supports needed by these young people in the future.

I feel that the crucial finding in this research is not only the difficulties and challenges that the child-heads face, but also their immense ability to be strong and defy the odds stacked against them. The strengths of this population are often unacknowledged and their voices are often not heard. Further research and supports should focus on attaining both of these in the lives of the young people.

This research had added to the limited research on child-headed households and should be the basis for more studies in the future. Upon completion of this research I have committed myself to continuing the struggle to help young carers have their voice heard, because they have so much to tell us if we not only listen but really devote the time to hear what they are saying. I see these findings as only the beginning of our understanding about these young carers in Uganda. In concluding I think it best to end with the wise words of one young person who said:

When there is hard days, [there's] no one to turn to. Because we are the child parents. We have no parents ourselves and [we are] a child as well.

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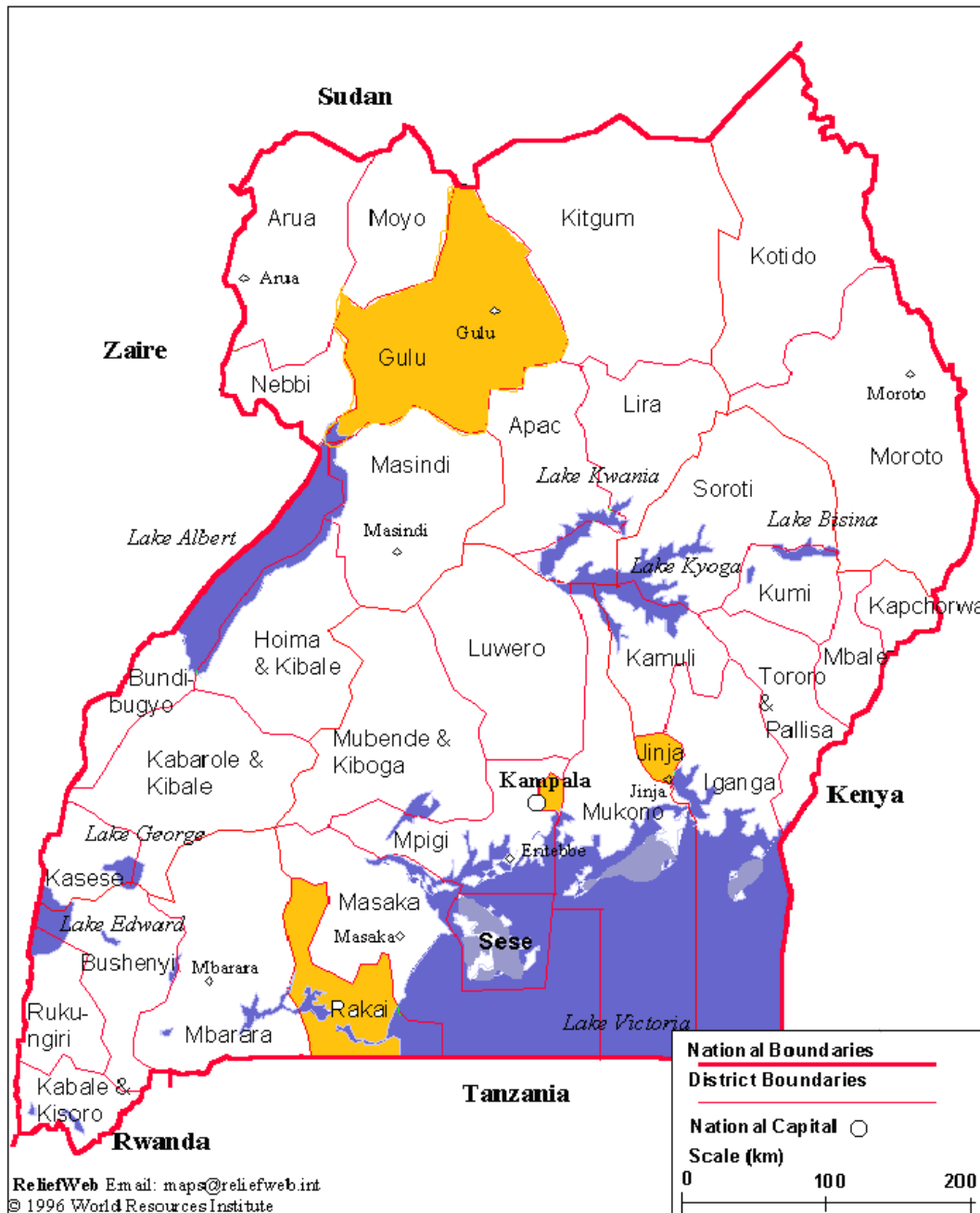
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APPENDIX I

Map of Districts in Uganda

UGANDA with district boundaries



 Districts which were a part of the study

APPENDIX II

UBC BREB Approval





*The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road,
Vancouver, B.C. V6T 1Z3*

CERTIFICATE OF APPROVAL - FULL BOARD

| | | |
|--|---|---|
| PRINCIPAL INVESTIGATOR: Grant Charles | INSTITUTION / DEPARTMENT: UBC/Arts/Social Work & Family Studies | UBC BREB NUMBER: H07-02895 |
| INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT: | | |
| Institution | Site | |
| N/A | N/A | |
| Other locations where the research will be conducted: The research will be conducted at the residence or in a community setting where the children live. The exact location will depend upon the wishes of the participants. | | |
| CO-INVESTIGATOR(S): Magdalene Athanasopoulos | | |
| SPONSORING AGENCIES: N/A | | |
| PROJECT TITLE: The Affect of Care-Giving on Orphaned Children Caring for Children in Uganda | | |
| REB MEETING DATE: February 28, 2008 | CERTIFICATE EXPIRY DATE: February 28, 2009 | |
| DOCUMENTS INCLUDED IN THIS APPROVAL: | | DATE APPROVED: March 27, 2008 |
| Document Name | Version | Date |
| Consent Forms: | | |
| Informed Consent | 2 | March 12, 2008 |
| Questionnaire, Questionnaire Cover Letter, Tests: | | |
| Interview Questions | 2 | March 13, 2008 |
| Other Documents: | | |
| Uganda Ethics RC1 | N/A | February 15, 2008 |
| Confidentiality Agreement | 1 | March 12, 2008 |
| Uganda Ethics RS6, | N/A | February 15, 2008 |
| Translator Confidentiality | 2 | March 12, 2008 |
| The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects. | | |
| <i>Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:</i> | | |
| <hr/> Dr. M. Judith Lynam, Chair Dr. Ken Craig, Chair Dr. Jim Rupert, Associate Chair Dr. Laurie Ford, Associate Chair Dr. Daniel Salhani, Associate Chair Dr. Anita Ho, Associate Chair | | |

APPENDIX III A

Uganda National Council for Science and Technology (UNCST) Approval

| | | |
|--|---|------------------------------|
| File No. <u>SS 2082</u> | Holder's Signature.  | Renewed until..... |
| Name. <u>MS. MAGDALENE ATHANASOPOULOS</u> |  <p>Certified Photograph Executive Secretary Uganda National Council for Science and Technology P.O. Box 6884, Kampala</p> | Executive Secretary |
| Address. <u>SOCIOLOGY DEPARTMENT, MAKERERE UNIVERSITY</u> | | Renewed until..... |
| Nationality. <u>CANADIAN</u> | | Executive Secretary |
| Title of Research Project. <u>THE EXPERIENCES OF ORPHANED CHILDREN CARING FOR CHILDREN IN UGANDA</u> | | Renewed until..... |
| Date of Issue. <u>15 APRIL 2008</u> | | Executive Secretary |
| Valid Until. <u>10 JULY 2008</u> | Executive Secretary | |

ANY ONE FINDING THIS CARD SHOULD REPORT IT AT THE
 NEAREST POLICE STATION.
 No. **245** 1071/1

THIS CARD IS A PROPERTY OF THE UGANDA GOVERNMENT

APPENDIX III B

UNCST District Letter- Kampala, Gulu, Rakai



Uganda National Council For Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Your Ref:.....

SS 2082

Our Ref:.....

15/04/08

Date:.....

Ms. Magdalene Athanasopoulos
Sociology Department
Makerere University
Kampala

Dear Ms. Athanasopoulos,

RE: RESEARCH PROJECT, "THE EXPERIENCES OF ORPHANED CHILDREN CARING FOR CHILDREN IN UGANDA"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **April 10, 2008**. The approval will expire on **July 10, 2008**. If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST. Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

The Resident District Commissioners of Rakai, Kampala and Gulu Districts in which the study will be conducted are informed by copy of this letter, and are kindly requested to give you the necessary assistance to accomplish the study.

Yours sincerely,

Leah Nawegulo
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION / CORRESPONDENCE

Plot 3/5/7, Nasser Road

COMMUNICATION

TEL: (256) 414-250499, (256) 414-705500
FAX: (256) 414-724290

APPENDIX IIIC

UNCST District Letter- Jinja



Uganda National Council For Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Your Ref:.....

Our Ref:..... **SS 2082**

Date:.....09/05/08..

The Resident District Commissioner
Jinja District

Dear Sir/Madam,

RE: RESEARCH CLEARANCE

We wish to introduce to you **Ms. Magdalene Athanasopoulos** who would like to carry out a research project entitled **"The experiences of orphaned children caring for children in Uganda"** between May 09, 2008 and July 10, 2008 in your district. The Uganda National Council for Science and Technology has approved the research project.

This letter is to request you to give the researcher the necessary assistance to facilitate the accomplishment of the research project. Your cooperation in this regard is highly appreciated.

Yours Faithfully,

Leah Nawegulo
for: Executive Secretary

UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION / CORRESPONDENCE

Plot 3/5/7, Nasser Road
P.O. Box 6884
KAMPALA, UGANDA.

COMMUNICATION

TEL: (256) 414-250499, (256) 414-705500
FAX: (256) 414-234579
E-MAIL: uncst@starcom.co.ug

APPENDIX IV

Letter of Information and Consent

THE UNIVERSITY OF BRITISH COLUMBIA



March 30, 2009

School of Social Work
2080 West Mall
Vancouver, B.C. Canada V6T 1Z2
www.swfs.ubc.ca

Letter of Information and Consent A Study of Orphaned Children Caring for Children in Africa

Investigators

Dr. Grant Charles
Assistant Professor
School of Social Work
The University of British Columbia
Vancouver, B.C., Canada
gcharles@interchange.ubc.ca

Lena Athanasopoulos, B.S.W., MSW (Candidate)
School Social Work
The University of British Columbia
Vancouver, B.C., Canada
athanML11_stcotw@hotmail.com

Purpose of the Study

I want to hear from young people, like you, who are caring for their brothers or sisters or other children in the community. I am hoping to learn about your experiences. I also hope to find out what kinds of services and supports are available to you, if you are able to get to the services, and what other types of services would help you out.

What will happen during the study?

My name is Lena and I want to learn what it is like to be you. You and I will set up a time to sit down and talk. We will talk about your experiences of caring for other children. If you need a translator, we can have one come to our talk. The translator can be here to help the two of us understand each other. He/she will tell us exactly what the other person has said. He/she has agreed to not tell anyone else about what we talk about. We will only talk one time for about an hour. We can talk wherever is most comfortable to you.

Potential Harms, Risks or Discomforts

It might be hard for you to talk about your experiences. It is okay to tell me that you need a break or you do not want to talk anymore. Remember that you do not need to answer questions that make you uncomfortable or that you do not want to answer. I will also stop our talk if I think that you need to take a break. We will only start to talk again if you want to finish. I can also give you some ideas of people to talk to if you need to talk to someone after we finish today.

Potential Benefits

I hope that what I will learn will help me understand more about your experiences as a young person caring for other children. I want to learn about what is hard in your life and what is easy for you. I want to look at how to best help you and children like you who are taking care of your brothers and sisters. What I find may not help you right now. But, it may help your community think of ways to help children like you. You will help to give me ideas of things that you need, so that I can share that with people who can try to make your wishes real some day. You will also help by telling me things that will make your life easier. I also want to tell people that there are lots of children who are taking care of their brothers and sisters in Uganda. If more people know about children like you then more people will be wanting to help. You are a special person. You are a strong person and you have many talents. You also are able to tell people about yourself because not many people understand what it is like to be you. Also, not many people would be able to take care of their brothers and sisters at a young age. You are a teacher for everyone that does not know what your life has been about. You have a powerful voice and I want people to hear what you have to say. It is very important. You are teaching all of us who do not know as much as you.

Who will know what I said or did in the study?

I will talk to people about what you tell me, but I will not tell them that it was you that said it. I cannot make sure that no one will find out that you talked to me. But the translator has promised to not talk about what we talk about either. Remember to only tell me what you are comfortable telling me. It is okay to tell me that you do not want to tell me something. I will not be upset.

I will try to keep your name secret from other people. I will not talk about your name with other people. But sometimes accidents happen and I can not promise that someone will not find out. I will never write your name on anything that I write for people that tells them what I have found out. I will also make sure that the tapes will be kept in a locked room so that nobody can get to them but me.

Only me, and my teacher in Canada, Dr. Grant Charles, will be able to look at the tapes of our talks. When we are done finding what we need, the tapes will be brought to Canada and locked away for 5 years before they are broken and thrown away.

Legally Required Disclosure

What we talk about will be told to other people. But who you are will not be told to other people. You do not have to tell other people that you talked with me today or what we talked about.

What if I change my mind about participating in the study?

It is your choice to talk with me. If you do want to talk with me and answer some questions, you can decide to stop at any time, even after you sign this form or after we start talking. If you want to stop talking, it is okay. I will not be mad or upset with you. It is hard to talk about our lives sometimes. If we stop talking then I will get rid of everything that you have told me unless you tell me not to. I will also break all of the tapes. If you do not want to answer some of the questions you do not have to, but we can still talk about other questions.

Information about the Study Results

When I have finished talking with many children like you, I will tell the schools in your community what I found. This will help them to know that there are kids in their community that feel the way you do and think about ways to help you. I will also tell your country what I have been finding out about you and all the kids I have talked to. This will help them to know how to make your life easier. They will not know who you are. I will just tell them what you, and the other kids I talk with, have told me. I hope that people in my country and your country can work together to help all kids to live a happy life.

Rights of Research Participants

If you have questions or want to know more about what I am doing, please call or find Dr. Doris Kakuru at Makerere University, P.O. Box 7062, Kampala, Tel.+256.41.540.650. She will be able to answer your questions or find me to answer your questions. She is helping me to talk with you and she has agreed to not tell anyone else your name or what you would like.

A group of people in both Canada and Uganda have decided that it is a good thing for me to talk with kids like you. But if you are not happy with something I have said or done, please go and talk to:

(local community leader): _____

He/she will help you and listen to what you have to say. You can find him/her at:

(contact information): _____

You can contact the Research Subject Information Services at:
Plot 3/5/7 Nasser Road, P.O. Box 6884, Kampala, Uganda, Tel.+256-414-250-499
if you have any questions or problems.

CONSENT

I (name of participant) _____, have been told about what Dr. Grant Charles and Lena Athanasopoulos will be doing with the assistance of Dr. Doris Kakuru. I have had the chance to ask questions about what Lena and I will talk about and why she wants to know more about me. I have also had time to think about if I want to be in the study or not. I know that I do not have to decide today if I want to talk with Lena, I can decide tomorrow if I want. Even if I sign this I can change my mind and decide not to talk with Lena at all. Even if we start talking I know that I can stop talking any time I want. I agree to talk with Lena.

Signature/ Mark of Participant

Date

Printed name of the Participant

Signature/ Mark of Witness

Date

Printed name of the Participant

APPENDIX VA

Interview Guide

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work

2080 West Mall

Vancouver, B.C. Canada V6T 1Z2

Tel: (604) 822-2255 Fax: (604) 822-8656

www.swfs.ubc.ca

March 30, 2009

Semi-Structured Interview Guide

(This is only a broad guideline-- it will take approximately 1 hour)

The purpose for gathering this information is to understand your experiences of caring for other children after being orphaned. I am trying to understand the ways in which children, like yourself, are surviving and coping with their role in order to uncover the most beneficial means of support. Please answer only those questions that you are comfortable answering. You have the right to discontinue your participation in the study at any time. Please feel free to ask me questions throughout if you do not understand something I have said.

Demographic Information:

Current Age:

Gender:

Cultural Background/ Tribe:

Main Language spoken:

Where born?

Where currently live?

Number of Children in the Household?

Factors Creating this Role Emergence:

How long have you been in this caring role? What age did you start?

Can you explain the events leading up to you taking on this role?

Daily Affect:

What was a typical day like before?

What is a typical day like for you now?

What are your interests outside your household?

Are you currently able to take part in these activities?

How they see the role:

How do you feel about being in your role?

How do you see your life as being different than other children your age?

If you were in this position again, would you take on the role or would you figure out something else to do?

Is there anything that you want to do but you cannot because you are in this role?

What is the best part of your life right now?

What is the worst part?

Services and Supports:

Do you have anyone to talk to about this issue?

Are there services available to you in your community?

Are you currently or have you ever received any form of services or support?

Is there any type of service or support that would help you out?

What do you need to make your life easier?

Experience:

Do you have any stories to share with other children like yourself?

Is there anything that you could say to someone to help them understand your situation?

APPENDIX VB

List of Interview Questions Added During the Study

1. If you could put your siblings in the care of another adult, would you? Why? Why not?
2. How do you make decisions in your family?
3. What are some of the things that you are really good at?
4. Tell me about your last happy/sad/scared memory or time?
5. If I had the power to grant you one wish, what would you wish for? If I asked you this same question right after your parents died, what would you have said?
6. If you go to an adult to ask them something or to talk with them, how do they treat/respond to you? How does this make you feel?
7. Other kids who have lost their parents are living in a different situation. If you had the choice, would you like to be in a different living situation?
8. Do you ever get time to yourself? What do you do?
9. When you stop sometimes, and are sitting back thinking.... What thoughts are coming into your head?
10. If you could set up a program, what would it be like?
11. Why have you not left yet?
12. How do you see your older sibling?
13. What resources did you need right after your parents died? How is that same/different from now?
14. How do you deal with that situation?
15. How did you learn how to parent?
16. Has the relationship you have with your brothers and sisters changed since you have taken on this role?

APPENDIX VI

Translator Confidentiality Agreement

THE UNIVERSITY OF BRITISH COLUMBIA



March 30, 2009

School of Social Work and Family Studies
2080 West Mall
Vancouver, B.C. Canada V6T 1Z2
www.swfs.ubc.ca

Translator Confidentiality Agreement A Study of Orphaned Children Caring for Children in Uganda

Investigators

Dr. Grant Charles
Department of Social Work and Family Studies
The University of British Columbia
Vancouver, B.C., Canada
gcharles@interchange.ubc.ca

Lena Athanasopoulos, B.S.W., MSW Candidate
The Department of Social Work and Family Studies
The University of British Columbia
Vancouver, B.C., Canada
athanML11_stcotw@hotmail.com

The investigators are placing a high level of responsibility and trust in you as a translator in this study. As part of your duties, you be hearing confidential information regarding participants in this study.

With respect to this information, I _____ agree to the following:

1. I acknowledge the confidentiality of all participant information. I agree that this information will not be revealed to or distributed to or discussed with anyone apart from the investigators involved in the study.
2. I will not attempt to alter, change, modify, add, or delete participant information as I am translating to the researcher. I will translate the information verbatim from the researcher to the participant and visa versa.
3. I will have no access to this information after my duties as a translator are completed.
4. I understand that failure to follow the above agreement will result in termination of my position translating in this study.

Signature _____

Date _____